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# ASSESSMENT AND PREDICTION OF LONG TERM PSYCHOLOGICAL OUTCOME AFTER INTENSIVE CARE.

# JOAN MACLEAN.

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy.

March 2000

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#### Abstract

The aim of this research has been the examination of the long term psychological consequences of admission to the Intensive Care Unit (ICU) for critical illness. The major objectives were first, psychometric assessment at specified intervals post-discharge, using the General Health Questionnaire, Rosenberg Self Esteem scale, and the Impact of Event Scale, and secondly identification of ICU related variables which influence psychological wellbeing and recovery.

The design was prospective and used survey methods. Seventy-two patients were recruited from the ICU at St James's University Hospital in Leeds. Data were collected at six weeks, six months and twelve months post-discharge. The initial analysis produced evidence of discrimination between subgroups, in particular age, length of stay in ICU, admission severity, indication for admission, communication, pre-existence of cancer, and the use of muscle relaxant drugs. Further analysis by way of a logistic regression identified four factors which may have predictive properties – age, admission severity, trauma and pre-existence of cancer. Patients from younger age groups reported more post traumatic stress symptoms than older patients; patients with pre-existing cancer also reported fewer post traumatic stress symptoms. Patients admitted following trauma reported poorer psychological outcome. Admission severity was negatively associated with psychological dysfunction, with those who were sickest on admission reporting fewer problems.

Symptoms of post traumatic stress disorder were found in a number of patients; at final follow-up 27% of the surviving sample had medium levels, and 27% high levels of post traumatic stress symptoms.

ICU patients form a fragile group to study and sample attrition was considerable. Nevertheless the findings are of interest to this developing research area and suggestions are made regarding their utilisation.

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#### **CHAPTER ONE. INTRODUCTION**

#### 1:1 Origins and rationale

The notion that stressful life events may predispose to poor health and illness is a familiar one, though the relationship between the two appears ever more complex. Extreme stress and a sense of wellbeing might be considered to represent opposing states. If the stress has itself been induced by illness, how hazardous is this to individual wellbeing? This research study deals with one aspect of this question by examining individuals who have experienced admission to an intensive care unit (ICU) as a result of critical illness, and by focusing on the psychological outcomes of their experience.

Enormous changes in health care have taken place during the past two decades. Nowhere are these changes more evident than in the field of intensive care. Fate used to decree our life span, now instead advanced medical science is able to prolong life for many of us. Constantly evolving technology has led to increasingly sicker patients being received into intensive care units, where highly trained staff, using appropriate emergency equipment and drugs, can reverse crisis after crisis. Increasing numbers of patients are being admitted to - or conversely being turned away from - these specialised units.

Ideas for the research evolved from the author's clinical experience as an intensive care nurse. From time to time surviving patients would return to the unit to see the staff who cared for them, usually after an appointment in the outpatients' clinic but occasionally by way of a specially arranged visit. In the main, seeing these people up and about and well was a highly rewarding experience, yet in the course of conversation ex-patients would quite frequently remark that despite their apparent return to physical health, the recovery felt incomplete. Accompanying relatives, too, might comment that the patient had still not returned to his or her previous self, sometimes months after discharge. Wellbeing seemed to be eluding these survivors, which given the effort invested both by the patients themselves, and the intensive care staff, struck a note of discord for the author. Further, the emotional problems reported by these surviving patients were apparently arising in the absence of any recognisable cerebral damage - for example by way of head injury or cerebrovascular accident - which could explain the apparent dysfunction. Naturally one expects this patient group to be transiently below par as a result of a critical illness and a spell in intensive care, but not to the extent that they are experiencing difficulties months down the line. It became apparent then that the consequences of the illness, for some survivors anyway, may extend beyond physical impairment: indeed it appeared that for a number of ex-ICU patients psychological problems might outweigh the physical effects of a period of critical illness.

What explanations are there for this mismatching of physical and emotional recovery? Without doubt the intensive care experience can be a forbidding one. Despite the clear intention on the part of the staff to provide help and support, the ICU can be a frightening place. Even healthcare staff, inured to hospital sights and sounds, but new to the ICU, will remark on the alien and intimidating nature of the environment. The unfortunate patient, then, may feel that he or she has entered some Kafkaesque system, waking to face isolation, bewilderment and fear in some dehumanised and tormented world.

Some individuals may be able to digest the intensive care experience more readily than others, as with any stressful life event - yet how are we to separate out those who will absorb the events easily, from those who will need help? One way to examine differences in response might be to relate the degree of, say, self efficacy or hardiness of the patient to his or her recovery after discharge. This might indicate whether such personality variables have a modifying effect on the intensive care experience. However this would depend on an accurate picture of pre-morbid personality: measurement of these factors immediately following a brush

with death may result in a tainted picture. Another possibility is to enlist the opinions and comments of the patient's relatives to form a picture of psychological function pre and post intensive care. Yet the fundamental interest here is the patient's own perception of his or her wellbeing, rather than assessment by proxy. Retrospective assessment of function is another option but this would be accompanied by its own complications, in particular that pre-admission disposition might be distorted when viewed through the lens of survival.

Premorbid psychological function, then, cannot realistically be assessed other than retrospectively. Would looking at postmorbid disposition, and at the survivors' return to a state of psychological wellbeing, generate useful information? What evolved from all these deliberations was the possibility of assessing, post discharge, a cohort of patients, and examining variables pertaining to their time in the ICU. From this it might be possible to discern what relationships, if any, existed between the actual ICU experience and subsequent recovery of psychological wellbeing.

The biomedical:psychosocial debate within healthcare has become almost as cliched as the nature:nurture debate within psychology. Knowledge from both "sides" of the debate is required to complete the picture of an individual's situation, and to inform care. It follows then that research in both biomedical and social sciences can generate information beneficial to the patient. The study described in this thesis is rooted in the research field of health psychology, in that it examines the emotions and perceptions of a group of patients in relation to a period of critical illness and the attendant events. Conceptual frameworks underpinning the work include those from stress and post traumatic stress, as well as theory relating to critical illness and subsequent recovery. The primary objective of the study was the assessment of psychological outcome and the identification, as far as possible, of predicting factors. Yet it is important to note a by-product of the work, which has been the generation of information which will benefit holistic practice within the ICU and seek to improve care for this patient group.

To that end, the major objectives of the study are as follows:-

1. Assessment of patients' psychological wellbeing at specified intervals following discharge from the ICU.

2. Identification of ICU related variables which influence psychological recovery following critical illness.

3. Examination of the relationship between findings from objectives One and Two.

4. Identification of factors which indicate risk and allow prediction of psychological outcome.

5. Development of a basis for suggesting targeted intervention.

Based on clinical experience, and the existing literature, the research questions are:-

- 1. Can different psychological outcome patterns can be discerned in different subgroups of ICU survivors?
- 2. Are there any factors related to the intensive care admission and experience which are predictors of psychological outcome in ICU survivors?

#### 1:2 The Intensive Care Unit

It is important to understand something about the aims of the ICU, and the procedures the patient may undergo, in order to convey successfully the potentially stressful nature of intensive care. The rapid evolution of high technology treatment has meant that the ICU has come to be considered an integral and familiar part of the hospital to the staff, yet it may remain a potentially upsetting and strange experience for patients and their families. Occurrences within ICU, coupled with the consequences of survival, may generate a great deal of stress for those who survive. The precise nature of the relationship between what happens in the ICU and any psychological sequelae is not fully established though it will be seen that a number of studies have considered this research question (Kornfeld 1969, Jones & O'Donnell 1994, Thiagarajan et al. 1994, Schelling et al. 1998, Jones, Humphris & Griffiths 1998). It appears that a short stay or a relatively minor event might evoke as much, and sometimes more distress than an extended, full-scale experience of the ICU. This observation of course simply bears out widely accepted transactional models of stress, yet it also gives rise to the research questions underlying this study: since adverse reactions are not apparent in every survivor, what, if any, are the principle predictors of psychological distress following the ICU experience? Further, is the occurrence of psychological dysfunction at an early stage postdischarge associated with problems in the long term - that is at one year? If, as is hypothesised, there are features either of the illness itself or of the environment, which predispose to psychological problems, then it is incumbent on ICU practitioners to work with these in order to minimise dysfunction and maximise wellbeing in survivors.

Within the ICU diagnosis, therapy and nursing care are directed towards reversing or at least stabilising disease processes, and returning the patient to the highest possible functional capacity his or her condition will allow. Yet the changes in the therapy offered, as ICU technology moves on apace, must be considered for impact on a number of factors: cost, staff development requirements, ethics, and not least patient outcome. As Weatherall has remarked in the British Medical Journal:-

"...In almost every field of modern high technology patch - up practice, patients are pushed to the extremes of their endurance, and not always for reasons that include a careful appraisal of what is meant by the quality of life."

Weatherall D. (1994 p1671)

Outcome audit has become a significant and necessary part of intensive care, and estimates of outcome and effectiveness are very important to this costly and complex field. Outcome research generated over the last ten to fifteen years has attempted to consider the lasting consequences for survivors not just by way of mortality rates and morbidity, but also in terms of quality of survival, including functional ability and quality of life as well as disease status (Bams & Miranda 1985, Hulsebos et al. 1991, Rustom & Daly 1993, Ridley et al. 1994). Though the data generated by quality of life studies have not been enlightening across the board, the efforts made to extend knowledge about clinical outcome should be welcomed by health practitioners and administrators alike.

The intensive care unit (ICU) exists within a hospital to provide specialised care for patients requiring respiratory support via mechanical ventilation, and/or treatment of organ failure. Patients admitted generally need treatment for some life threatening yet potentially reversible condition, alternatively they may need support pending a definitive diagnosis, or while waiting to undergo surgery or receive an organ transplant. On some units patients shown to have suffered brain stem death will be ventilated and supported for short periods following diagnosis of brain stem death in order to preserve organs for donation. Disorders treated in ICU include respiratory or circulatory failure, which may or may not be compounded by haematological, gastrointestinal or neurological dysfunction, sepsis, or renal or hepatic failure.

St James's University Hospital, Leeds, which was the research setting for this project, opened a new ICU in December 1994. This unit is now one of the largest general ICUs in the United Kingdom. Adult bed provision currently stands at eleven beds - sadly cash restraints play a part here since there is in fact room for a further seven beds. The General Infirmary at Leeds, which lies on the other side of the city, joined St James's University Hospital in April 1998 to form one of the largest hospital trusts in the United Kingdom. Adult intensive care provision at the General Infirmary - not accessed during this particular study - stands currently at fourteen cardiac beds, seven neurosurgical beds and seven general beds. Each ICU bed costs approximately £250,000 per year to keep open, including the cost of twenty four hour individual nursing, and use of high technology equipment (1999 estimates, St James's University Hospital).

Today in the United Kingdom the majority of ICUs are staffed by specialised teams comprising intensive care trained medical, nursing, technical and administrative personnel. There will also be access to physiotherapists, pharmacists, radiographers, dieticians and other health professionals. A senior medical practitioner - usually an anaesthetist, and now often with specific intensivist training - and a senior nurse, will be in overall charge of the unit. However patients are also under the care of the admitting surgeon or physician and their teams, thus the ICU tends to function with a considerable degree of crossover of care, such that the patient's management will be influenced by a number of people.

Other specialised units may be located within the same hospital - for example the high dependency unit (HDU) which provides intermediate care between the ICU and the general ward; also the coronary care, renal, hepatology, neurosurgical or burns unit, as well as possibly separate neonatal and paediatric ICUs. However most hospitals are neither large nor affluent enough to provide such all-embracing intensive care, and different units may be dispersed across a health region.

Though patients may be admitted to the ICU for various reasons, one of the commonest indications for admission to ICU is respiratory failure. Respiratory failure results in hypoxia - that is lack of oxygen supply to tissues - and very often in retention of carbon dioxide. Hypoxia induces a metabolic acidosis, that is a lowering of the blood pH. This occurs as a result of accumulation of lactic acid, the product of anaerobic metabolism. The acidosis reduces cardiac function leading to still further hypoxia. The outcome of this cycle if untreated is death. Oxygen delivered via face mask or nasal cannulae may be administered in an attempt to treat hypoxia; if respiratory failure cannot be dealt with satisfactorily by oxygen inhalation therapy then mechanical ventilation of the lungs may be required.

Mechanical positive pressure ventilators blow air - or some prescribed composition of gases into the lungs via an endotracheal tube introduced nasally, orally or via tracheostomy, and secured by inflation of a low-pressure cuff. Tracheal intubation allows both the delivery of gases and the suction removal of secretions, while the cuff also offers protection from inhalation of gastric contents in the deeply unconscious patient.

Modern mechanical ventilators allow a range of assisted ventilation methods. Modes of ventilation vary, though all have the same objective, that is to improve gaseous exchange and ensure adequate oxygen delivery. One commonly prescribed mode is intermittent mandatory ventilation (IMV) whereby the patient is able to take spontaneous breaths in between mandatory breaths from the ventilator. In this way the patient can ventilate spontaneously, yet is guaranteed a predetermined minute volume (the volume of gas moved in and out of the lungs over sixty seconds) should no respiratory effort occur.

Arterial oxygenation and functional residual capacity (the volume of air remaining in the lungs at the end of expiration) may be improved by elevating airway pressure during expiration either by applying positive end expiratory pressure (PEEP) to the ventilator, or by connecting the spontaneously breathing patient to a continuous positive airway pressure (CPAP) system. High frequency jet ventilation delivers small tidal volumes (the volume of gas moved in and out of the lungs in one breath) at a rapid rate, reducing peak airway pressure and protecting cardiac output. It may offer advantages in cases of adult respiratory distress syndrome (ARDS) or bronchopleural fistula.

Aside from respiratory support, and whatever the patient's original problem, general management of the critically ill involves a variety of procedures which collectively contribute to the patient's experience. Circulatory support will require invasive monitoring by way of central venous, radial and pulmonary arterial catheterisation; bladder catheterisation may be necessary to monitor renal function, and if renal function becomes grossly impaired then artificial haemofiltration will also be required.

The systemic response to physiological stress such as that visited upon the critically ill may include slowing or cessation of gut function plus a risk of ulceration. A nasogastric tube will be inserted to allow aspiration/draining of gastric contents. Maintenance of nutrition may be by enteral feeding via the nasogastric tube; alternatively a dedicated central venous catheter will be inserted to allow total parenteral nutrition (TPN) - infusion of a solution of protein, carbohydrate, fat, electrolytes, vitamins, trace elements and water.



These sound - as indeed they are - potentially traumatic or stressful experiences. Figure 1:i illustrates the overwhelming amount of equipment surrounding the ventilated patient on ICU. Initial intubation and line insertion may need to be performed under anaesthesia; subsequently the patient must receive adequate analgesia and if necessary sedation. The intubated patient, who cannot speak since the endotracheal tube passes through the vocal cords, may be too disorientated or incapacitated to communicate adequately by non-verbal means. A number of methods may be employed for the responsive intubated patient, for example pencil and pad, a letter or symbol board which the patient can point to, magic slates, or just a system of hand squeezes or eye blinks. These are good alternatives but time consuming and thus wearying for the patient and, on occasion, the staff. Experienced ICU staff may become adept at lip reading. The extubated patient, too, may be exhausted, confused, or receiving strong medication, rendering him unable accurately to communicate with people and report pain, discomfort, or anxiety.

These communication difficulties may lead to problems, especially if compounded by pain, fear and incomprehension of procedures and treatment (Holloway 1989). If the patient has been admitted electively, it is highly likely that some information will have been given as a forewarning, although the sensation of waking attached to a ventilator may be a shock even to the best prepared patient. An unplanned admission, however, means that intubation and ventilation will have taken place under emergency conditions and little or no psychological preparation will have been possible.

Thus the ability to anticipate and interpret patients' pain and distress are extremely desirable skills in intensive care staff. Holloway (1989) suggests that good care - constant nursing presence, anticipation of need, eye contact, explanation and reassurance, and (intermittently) the presence of a supportive relative, can reduce considerably the need for verbal communication by the patient.

The need for sedative drugs varies, some patients by nature of their disease may be minimally conscious, others may be awake but tolerant of the ventilator, and receiving adequate pain relief yet apparently alert. In the ICU context sedation covers both sleep, and relief from anxiety when awake. Anxiolytic drugs commonly in use include the benzodiazepines - diazepam, lorazepam, midazolam, as well as such drugs as propofol, ketamine, chlormethiazole. In the longer staying patient who needs to reset a sleep/waking pattern, simple night sedation - for example a drug like temazepam - may be administered. The chosen combination of analgesia and sedation will vary according to unit policy, individual practice and the clinical picture, and doses and drugs will undergo regular review in order to maximise comfort and minimise anxiety.

Pain relief is also fundamental to the management of the ICU patient. Pain may arise both from the initial clinical problem - for instance a ruptured aortic aneurysm - as well as from the invasive procedures involved in support and monitoring. Intravenous infusion of opiates or their derivatives will be commenced, augmented by bolus doses just prior to painful procedures. Other methods of pain relief include local nerve block or epidural infusion of opiates, particularly following surgery.

Satisfactory management of the ICU patient then requires a combination of drugs to ensure pain relief and optimise comfort and wellbeing. Sedation levels are assessed constantly: as recovery occurs then attempts may be made to keep the patient alert during the daytime though continuing the use of bolus doses for moving and handling or unpleasant procedures keeping the bulk of sedative drugs to be administered at night.

#### 1:3 Overview of the thesis

Following the introductory chapter, Chapter Two reviews the literature on intensive care psychology, including early studies of short term problems and ICU psychosis, research into

longer term problems, and more recent proposals of post traumatic stress after ICU. In Chapter Three the concept of stress is examined, including discussion of the different approaches to stress, and of some of the mediating factors which have been recognised. This chapter ends by focusing on the stress specifically experienced by patients receiving intensive care. A discussion of post traumatic stress disorder (PTSD) follows in Chapter Four, which considers the recognition of the syndrome, and the different conceptual models of PTSD which have been developed.

The long term psychological effects of intensive care have the potential adversely to affect quality of life, and this concept is the focus of Chapter Five. Health related quality of life as an outcome measurement is discussed, and contrasted to outcome prediction in ICU using scoring systems. Finally literature relating to quality of life after intensive care is reviewed, demonstrating the burgeoning interest in this area.

Having considered the background to the study, the thesis moves on in Chapter Six to a discussion of the instruments used to measure psychological outcome, including description of their development and a rationale for their use within this study. Chapter Seven deals with the methodology of the study, and the results are described and discussed in Chapters Eight to Eleven. Chapter Twelve, the final chapter, offers a concluding discussion, including the strengths and weaknesses of the design, and makes some recommendations based on the overall findings.

#### **CHAPTER TWO. INTENSIVE CARE PSYCHOLOGY**

The scope for psychology within intensive care is vast, and a wealth of literature is available reporting studies of the ICU environment, and its effects on those who have encountered it. Much of the extensive literature has centred on the acute and immediate psychological problems inherent in the treatment and management of the critically ill (Kornfeld 1969, Ashworth 1980, 1984, 1990, Simpson-Wilson 1987, Dracup 1988); these findings have helped to fuel interest in more lasting effects. It is important to acknowledge sub-divisions of ICU psychology other than patient psychology. A large body of research exists which focuses on problems encountered by the personnel which staffs the ICU; also the considerable emotional strain experienced by the relatives or "significant others" of patients is a well researched area (Molter 1979, Coulter 1989, Wilkinson 1995).

This section of the thesis surveys the literature concerning psychological outcomes following ICU survival. It begins with early reports of psychological disturbance within the ICU itself before moving to consider research which focuses on the psychological quality of survival. It will be seen that despite obvious interest in patient psychology within ICU, psychological and social aspects of survival were a poorly served area of ICU follow-up until the relatively late discovery of "quality of life" by intensive care researchers. The current state of psychological outcome research within the United Kingdom is reviewed, and studies relating to the possibility of the ICU as a source of post-traumatic stress are included, though this aspect is considered in more detail in Chapter Four of the thesis.

#### 2:1 Short term problems and ICU psychosis.

Patients with a critical illness have as a group been studied in detail, with some emphasis on short term problems such as procedural distress and communication difficulties (Ashworth 1980, 1984, Simpson-Wilson 1987, Turnock 1989, Pennock et al. 1994, Porter 1995). Other research has involved itself with the fears and anxieties generated by the ICU surroundings, and with the need to humanise the harsh environment in which the patients and their families find themselves (Ashworth 1990, Hudson 1993, Halm & Alpen 1993, Calne 1994).

Initial interest in the psychological aspects of intensive care tended to focus on behavioural changes witnessed within the ICU itself. This is not hard to understand. Here was a population, subjected to strange and frequently unpleasant experiences in the name of therapy, whose potential for psychological disturbance was self-evident. Until relatively recently, however, far fewer reports were available on the longer term psychological sequelae for ICU survivors. Any prolonged emotional impact of admission and treatment - though not ignored entirely - was initially not a prime consideration in outcome research, and the need for more long term studies was noted in the medical press some years ago (Lloyd 1993), coincidentally just as the idea for this study was seeding.

The sensory imbalance imposed by intensive therapy and ventilatory support has been seen to have profound effects on many patients, culminating in a recognisable psychosis in some individuals. ICU psychosis, manifesting as impaired responses such as depression, anxiety and delirium, is a disorder which is thought to result in large part from the constant seesawing between sensory overload and sensory deprivation experienced by the ICU patient. It has been noted that the psychotic symptoms exhibited by sufferers parallel those induced by sleep deprivation (Kornfeld 1969) and some categories of psychological torture such as isolation or exposure to white noise (Dyer 1995). Sleep disturbance alone can result in problems on discharge to the ward, with patients reporting restlessness, memory and judgment impairment (Dracup 1988, Topf et al. 1996). Certainly noise and activity within the ICU may have negative effects on sleep for recovering patients, rendering them liable to confusion and weariness. Further, given the importance attached to sleep with regard to restoration of energy

and reinforcement of protein synthesis and immune function (Horne 1988, Topf et al. 1996) attention to noise levels and promotion of sleep are clearly important aspects of intensive care.

The condition of ICU psychosis was described by McKegney (1966) as a "madness in ICU", an unfortunate spin-off of medical progress. Such early reports of psychosis or "ICU syndrome" emerged from observation of patients undergoing cardio-pulmonary bypass for open heart surgery, in whom a high rate of hallucination, agitation and confusion was documented. Much of this psychological disturbance was related to the disorientating and threatening environment within early cardiothoracic ICUs (Solomon et al. 1957, Egerton & Kay 1964, McKegney 1966).

Kornfeld (1969) observed that in many patients symptoms were alleviated on transfer back to the standard hospital ward. His was one of the first studies to make recommendations in relation to psychosis, in particular encouragement of uninterrupted rest or sleep periods, reduction of unnecessary noise and light, particularly at night, and an attempt to orientate patients by way of clocks, calendars and a view through an outside window wherever possible. Of course some of the neuropsychological consequences of cardiac surgery can be attributed to the use of cardiopulmonary bypass itself and the attendant risks of reduced cerebral perfusion and microembolism (Abrams 1967, Taylor 1982, Mills & Prough 1991), which could explain some of the frequent reports of ICU psychosis in cardiac surgery patients.

Though some of the bizarre sensory experiences within ICUs have been minimised today - for example twenty-four hour full lighting is viewed with disfavour, and the frequent, though not constant, presence of relatives is now generally encouraged - a syndrome may still occasionally occur wherein the conscious patient displays fear, confusion and utter disorientation (Hopkinson & Freeman 1988, Dyer 1995). It has been noted moreover that the use of a variety of terms, and different interpretations of confusional states by medical and nursing staff, may mean that many cases of ICU psychosis are missed (Anetth 1994). It appears that

ICU psychosis is a complication, arising during the acute period of illness within the ICU, which has the potential for repercussion in the recovery period.

Even in the absence of exaggerated responses, individuals may still display some adverse reaction to the stress generated by the ICU experience - it has been estimated that patients spending more than five to seven days in intensive care run a risk of up to 30% chance of significant mental aberration such as hallucination, insomnia and confusion (Kleck 1983). Pauser et al. (1984) examined 182 patients for behaviour and personality changes over three years following discharge, finding up to 69% of patients reporting moderate problems with social readjustment, and up to 22% serious problems with the same. In comparison, anxiety and psychological problems in post myocardial infarction patients, treated in coronary care units, have been reported at approximately 20% (Thompson et al. 1996). Discussion of patient psychology within and beyond coronary care units (CCUs) is a topic in itself, and it is acknowledged that CCU patients endure somewhat different, though nonetheless distressing situations, not least consciousness and awareness of much of their time in CCU, with attendant anxiety and uncertainty.

#### 2:2 Nursing involvement within ICU.

A number of studies have concentrated on the distinctive part played by nursing staff in the psychological care of patients undergoing intensive care. Patient psychology features strongly in nursing theory relating to acute illness, as evidenced by models such as Neuman's (1989). Holism is implicit in this model, which perceives the individual as a complete system comprising physiological, developmental, sociocultural and psychological subsystems. Nursing assists the patient in the attainment and maintenance of equilibrium in each system: of paramount importance is the individual's adjustment to stress in both his internal and external environment. The continuous one-to-one nursing practised within the ICU provides a unique

opportunity to assist the patient in the maintenance of psychological equilibrium during a potentially very stressful life event - and thus to achieve this "system stability".

Ashworth (1980) conducted a study of communication within ICU, across five units in the north west of the United Kingdom. Data collection took the form of observation of nursepatient communication within the unit, interviews with patients after transfer out, and interviews with the ICU nurses themselves. Of nineteen patients interviewed, three had no recall for the time in ICU. Of the sixteen who did have some memory, seven remembered difficulties communicating with staff. Interpretation of the results is not entirely straightforward since the study had attrition problems, which are to be expected given the nature of the group under study. Nevertheless the study provided research-based evidence of problems with communication in ICU - in particular lack of feedback from patients, and inability correctly to interpret their needs throughout a nursing shift. Its recommendations included formal assessment of patients' communication needs, and staff development in communication skills.

Engberg (1991) has examined nurses' interpretation of patient withdrawal in ICU and subsequent nursing intervention, while more recent studies have described the benefit to patients and their families of clear information about problems which may be encountered after discharge (Jones & O'Donnell 1994, Waldmann 1998). Nursing research conducted in the USA (Kerr et al. 1991) has considered psychological outcomes in the critically ill by studying trends in patients' response patterns and their relationship with patient satisfaction and health status. This study expands such research, by examining the less immediate effects of the stressors inherent in the ICU, and by highlighting potential problem areas for patients.

#### 2:3 Longer term problems

As discussed in Chapter One, outcome audit has become a significant and necessary part of intensive care. Mortality within the ICU has been studied and recorded widely; it has been the basis of intensive care audit since the inception of such accounting processes. Initially data relating to psychological outcome emerged almost as a by-product of attempts to audit ICU activities and successes. One of the earliest reports of emotional wellbeing after intensive care can be found in an account of the 1952 polio epidemic in Copenhagen (Lassen 1953). Treatment methods during this epidemic changed from ventilation via cuirasse respirators mechanical devices fitted to the chest - to the use of positive pressure ventilators requiring endotracheal intubation of the patient. These new appliances, prototypes for today's mechanical ventilators, were manually operated by medical students working shifts. Consequently the patients had constant bedside company as well as surveillance, and Lassen described the beneficial effect of this new technique not only on mortality rates, but also on the morale of surviving patients. The allocation of a professional attendant to each patient has persisted and this individual attention has become one of the most basic principles of intensive care, though in some units the introduction of remote monitoring from a central nursing station has reduced the constant presence of an attendant at the bedside.

More recently, outcome research has begun to consider the lasting consequences for survivors not just by way of mortality rates and morbidity, but also in terms of quality of survival. As Rowan (1992) has noted, examination of the results of intensive care for specific patient groups also produces useful data regarding the quality of survival. Research has included, for example, studies of outcome for leukaemia patients requiring intensive support during chemotherapy (Yau et al. 1991), functional outcome in the elderly following ICU admission (Mahul et al. 1991) and examination of psychological dysfunction after myocardial infarction (Wishnie et al. 1971, Griego 1993).

Drawbacks in outcome research have included the limitations of data from narrowly defined patient groups, and the prevalence of single-unit studies. Although many useful data have emerged from individual ICUs, multicentre studies may produce findings which are more generalisable. Rowan's own study involved co-ordinating data collection from twenty-four ICUs across the UK, describing outcomes in relation to quality of life at six months postdischarge. These data included measures of functional ability, perceived health status and social factors. Among the numerous findings from this nationwide study were reports of good physical health for the majority of survivors, and fairly low rates of depression and anxiety, though a number of respondents reported some degree of dysfunction within the social dimension. These findings stand in contrast to the results of the earlier study by Pauser et al. (1984), where a high proportion of participants reported at least moderate long term social readjustment difficulties. Since completion of Rowan's research study, the UK Intensive Care National Audit and Research Centre (ICNARC) has been established whose aim is to provide an independent national resource for the evaluation of intensive care and its outcomes, in terms of mortality and morbidity. The centre's inception came in response to the lack of hard evidence that widespread use of intensive care had improved patient survival, and the need to monitor care more rigorously (Icnarc 1994). Though ICNARC aims to evaluate both specific aspects and the overall impact of intensive care, to date there is no UK working group looking specifically at quality of life for ICU survivors. Quality of life as a psychological concept, and its measurement in relation to intensive care, are discussed in greater depth in Chapter Five.

Estimates of outcome are of course important to the costly and complex field of intensive care. Medically derived outcome prediction models such as APACHE II or III - (Acute Physiology And Chronic Health Evaluation, Knaus et al. 1985) - will allow prediction of survival chances based on separate health markers. Such models have assisted in the management and evaluation of intensive care.

An association between high APACHE II and TISS (Therapeutic Intervention Scoring System) scores and poor quality of life has been reported (Sage et al. 1986). In addition, scored pre-morbid and chronic health status have been shown to have predictive ability with regard to quality of life post-discharge (Goldstein et al. 1986, Sage et al. 1986, Yinnon et al. 1989). The use of scoring systems for outcome prediction in ICU is discussed in greater detail in Chapter Five. But the basic premise of such models - prediction based on risk stratification - is of relevance to consideration of the psychological sequelae of the intensive care experience. Important outcome variables such as quality-of-life and mental wellbeing, inextricably linked to physical condition, can and should be included in prognostic estimates.

#### 2:4 Recall of the ICU

Recall of the intensive care experience is worth examination in relation to subsequent recovery, though naturally recall of the experience may be affected by a number of factors, not least the mixture of potentially mind altering drugs administered, and the altered cerebral blood flow which may result from a haemodynamically unstable state. The terms "awareness" and "recall" are sometimes used interchangeably in discussion of ICU sedation levels. The distinction between the two must be considered since the two things relate to differing levels of consciousness. Cheng (1996) defines awareness as a state of awakeness and cognisance, and recall as explicit memory for events. In the ICU the use of sedative and analgesic drugs, and anaesthetic agents, is a major aspect of patient care. Pain must be controlled and anxiety and distress minimised; good management of the critically ill patient will include as an imperative assessment of the apparent level of sedation and comfort by experienced staff. Yet as Cheng (1996) points out, not every patient suffering increased mental distress will present with a similar increase in agitation: physical signs may be masked by neuromuscular blocking agents (drugs inducing temporary paralysis) or the restraining effect of ICU apparatus.

Scales have been developed specifically for ICU use, in an attempt to assess the adequacy of sedation. Scoring systems may use numbers or points (Ramsay 1974, Chernik et al. 1990) or a visual analogue (Smith et al. 1994). The common aim is to quantify level of sedation by way of motor activity and response to stimuli. Other methods employed to assess sedation level or depth of anaesthesia include electroencephalogram (EEG) recording, and measurement of auditory evoked potentials. These have been of use in anaesthetic research but are as yet probably not practical methods for everyday ICU use.

Studies of awareness during, and recall following general anaesthesia - delivered for surgical purposes rather than ventilation on ICU - have generated a large body of information. Varying levels of anaesthesia have been described, ranging from wakefulness with light sedation, relative analgesia and full recall, through a state of apparently rational response yet absolutely no recall, to deep anaesthesia with no response - though even in profound anaesthesia it may be possible to elicit a response to verbal stimulation (Jessop & Jones 1992). Miller (1987) has described several types of memory in patients who have recovered from general anaesthetic, for events and/or dialogue which took place during the period of apparent unconsciousness. Some patients were able to produce verbatim recall, others required cues, while a few had solely subconscious recall, elicited only via hypnosis.

Jones & Koniezko (1986) have disputed the commonly held notion that recall is linked with awareness, that is that it occurs because the anaesthesia was comparatively light for some duration. Their suggestion is rather that some anaesthetic concentrations will allow cortical input and registration despite the semblance of lack of consciousness.

Recall for events occurring specifically within intensive care, as opposed to during anaesthetic, has been the subject of some studies. Egerton & Kay (1964) undertook one of the earlier reported studies, an examination of patients discharged from a respiratory support unit. They found evidence of patient recall for several details of care, including unpleasant memories of

endotracheal suction and arterial blood sampling. Hewitt (1970) found that although around 65 patients from a sample of 100 were able to say how long their stay in ICU had been, more than 70 could not recall major procedures like ventilation or extubation. For those who did demonstrate recall, procedures such as endotracheal suction, and removal or manipulation of drainage tubes were quite vivid and concerning. Interestingly there was little difference in recall between those patients who were mechanically ventilated and those who managed spontaneous respiration.

Bergbom-Engborg et al. (1988) interviewed ICU survivors following transfer out of the ICU and found 52% of a sample of 304 to have recall for treatment and ventilation. A sex differentiation was noted with women having less recall than men; this difference became more marked in patients over the age of sixty. More recently Holland et al. (1997) studied patients' recollections and satisfaction with care received in the ICU; despite some vivid memories, those patients who reported the least stress from the experience were those who recalled staff demonstrating caring attitudes and an ability to anticipate needs. From the literature, it does seem that a significant proportion of survivors is able to remember particularly stimulating moments of the treatment received in the ICU, and Cheng (1996) has suggested that suppression of awareness and recall may help prevent psychological problems following discharge from the unit.

#### 2:5 Post traumatic stress and the ICU

In conjunction with moderate psychosocial complaints like anxiety and insomnia, recurrent and intrusive recollection of ICU events by way of nightmares and unpleasant memories has been reported. Daffurn et al. (1994) examined patients three months after discharge from ICU and found that despite most having returned to near normal health, many reported mild to moderate psychological sequelae including insomnia, irritability and anxiety. In addition, a third of the research sample (n = 54) reported signs of stress possibly related to the experience

including nightmares, hallucinations and intrusive thought. Indeed some researchers suggest that a number of patients may well fulfil criteria for post-traumatic stress disorder after discharge (Williams et al. 1994). A qualitative study by Hall-Smith et al. (1997), though not diagnosing PTSD formally, derived from its data themes such as flashbacks and vivid dreams, suggesting the presence of some post-trauma problems. In the same year Koshy et al. (1997) reported a PTSD incidence of 15% in a group of ICU survivors at twelve months post discharge.

Schelling et al. (1998) recently studied a group recovering from adult Acute Respiratory Distress Syndrome (ARDS) in an examination of post traumatic stress in survivors. ARDS is a life threatening condition which necessitates intensive and potentially very distressing intervention within the ICU, using various ventilation techniques including use of the high frequency "jet" ventilator described in Chapter One. Schelling suggests links between the traumatic events endured in the ICU - acute anxiety, awareness of severe respiratory insufficiency, intrusive and repetitive noise from the jet, hallucinations and nightmares during treatment - and long lasting effects on emotional wellbeing. The majority of survivors examined in this study reported only a moderate degree of physical impairment, but a high frequency of significant psychosocial impairment. The reported incidence of PTSD in the ARDS survivors - 27.5% - was significantly higher than that in the control group.

However, conclusions should perhaps be drawn cautiously from results with ARDS patients. Hopkins et al. (1999) have measured impairment in survivors of ARDS, via a battery of tests at discharge, and then again at twelve months. Cognitive function tests included the Wechsler Adult Intelligence Scale, Rey Auditory Verbal Learning Test, and tests of verbal fluency. At discharge from the ICU 100% of the sample of 55 exhibited cognitive impairment, and at twelve months 17 (30%) demonstrated continued decline. Seventy-eight percent of the sample had problems with at least one aspect of cognitive function, from memory, mental processing speed, attention or concentration. This may stem from the ICU experience alone, but it must be noted that ARDS causes severe lung damage and is characterised by episodes of profound hypoxaemia or reduced oxygenation. Mortality is high, respiratory support aggressive, and the chance of hypoxic cerebral damage is relatively great, part explanation perhaps for the levels of impairment detected.

The importance of recognising PTSD in patients within the ICU - for example following road traffic accidents or violent incidents - is acknowledged (Demi & Miles 1983, Campbell 1995). Yet the ICU experience *per se* has the potential to be quite stressful, and it is quite feasible that the seeds of stress disorder may be sown here, a further indication for psychological follow-up.

Patient psychology should be the domain of all health professionals working in intensive care, and both the unit staff and the patients' families play a part in the protection of patients' mental wellbeing. Studies relating to patient psychology have contributed greatly to improved practice within ICUs (Kornfeld 1969, Ashworth 1980, Simpson Wilson 1987), for example by alerting staff to the potential for distress, and suggesting attention to the patient's environment. Successful outcome for ICU survivors is difficult to define since so many variables need to be taken into account, but what emerges clearly from the literature discussed is the indication of a need for further study to examine more closely these potential hotbeds of psychological disorder.

#### **CHAPTER THREE. STRESS IN THE INTENSIVE CARE UNIT.**

".... I attempted to rise, but was not able to stir: for, as I happened to lie on my back, I found my arms and legs were strongly fastened on each side to the ground;......I could only look upwards: the sun began to grow hot and the light offended my eyes."

from Jonathan Swift, "Gulliver's Travels Part One: A voyage to Lilliput." p12

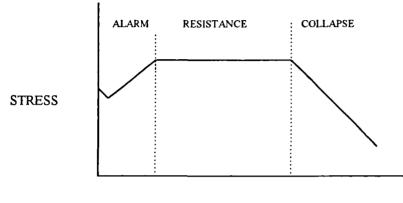
#### 3:1 Concepts of stress.

During the past two decades stress has become a vogue word used, often loosely, to explain a myriad of negative outcomes. A diagnosis of stress may be invoked when events are deliberate - for instance a change of job or a house move - or when unplanned situations arise such as redundancy, bereavement or sudden critical illness. The positive aspects of stress - eustress - are acknowledged by the bulk of research as necessary for motivation and development, yet stress remains a label for a large spectrum of disturbing symptoms, both physiological and psychological. Perspectives on stress have evolved from the psychobiological approach adopted in the first half of the twentieth century, to the transactional or cognitive-phenomenological approaches favoured in contemporary psychology.

#### 3:2 The response based approach

Early approaches to stress involved physiological or medical perspectives whereby stress was viewed as a largely somatic response to a disturbing stimulus. Selye (1936) noted that severe, prolonged exposure to stress would ultimately exhaust the ability of a system to adapt or cope. He proposed a universal, integrated response to stress which could be divided into stages - alarm, resistance and ultimately collapse. This General Adaptation Syndrome (GAS - Selye 1956) is represented diagrammatically in Figure 3:i

Figure 3:i. The General Adaptation Syndrome



TIME

after Selye 1956

The <u>alarm</u> stage includes the immediate psychophysiological responses brought about by the autonomic nervous system - the "fight and flight" response as described by Cannon (1935). Sympathetic nervous activity results in release of adrenaline and noradrenaline by the adrenal medulla, whose action produces tachycardia, increase in arterial blood pressure, and dilatation of the bronchi - all in an effort to boost oxygenation and increase performance. Meanwhile gastrointestinal activity diminishes allowing diversion of blood to the cardiovascular and respiratory systems, and thyroxin and cholesterol production increase in order to boost metabolism and energy.

Simultaneously, stress conditions result in the release of corticotrophin-releasing hormone (CRH) by the hypothalamus. This is carried by portal circulation to the anterior pituitary

where it causes the release of adrenocorticotrophic hormone (ACTH) into the general circulation. ACTH acts on the adrenal cortex to release cortisol which has powerful effects on the body tissue. Stored glycogen in the liver is converted to glucose, whose uptake is inhibited by all tissues other than the brain, where requirements are vastly increased; cortisol also stimulates the breakdown of proteins to amino acids in readiness to repair possible tissue damage. Further, it regulates vascular dilatation thereby helping to maintain blood pressure. The stress response is further complemented by release of endorphins from the hypothalamus supplying natural analgesia in the short term.

Stage two - <u>resistance</u> - involves continued attempts to adapt to the stress, thereby requiring further catecholamine and cortisol release. The stress response is perpetuated via the pituitary-adrenal axis - a closed circuit or feedback loop, as seen in Figure 3:ii below.

#### Figure 3:ii. The hypothalamic-pituitary-adrenal axis

Ť	Sympathetic nervous system	Ļ
Adrenaline Noradrenaline		Hypothalamus
Ť		Ļ
Adrenal glands	←	Anterior pituitary

Adrenaline and noradrenaline act as neurotransmitters within the sympathetic branch of the autonomic nervous system.

Circulating cortisol levels regulate secretion of ACTH - and thus cortisol itself - by negative feedback on the anterior pituitary and the hypothalamus, though this mechanism may be overridden if the body is responding to rapid, unrelenting stress. Normal body function remains suppressed, with attendant detriment to health. Prolonged tachycardia and hypertension may result in cardiac or cerebrovascular difficulties, while shut down of the gastrointestinal system predisposes to peptic ulceration. Cortisol has a marked immunosuppressive effect: prolonged over-production interferes with lymphocyte maturation and function resulting in lowered immunity. Should stress remain unrelieved then a final stage of exhaustion or <u>collapse</u> is reached. Our powers of resistance are not infinite and eventually become depleted.

It has been suggested that the ultimate outcome of unmitigated stress is death (Selye 1956, Harrison 1984). Threat appraisal triggers autonomic activity, setting in motion the physiological events described above. The increased catecholamine activity and endocrine secretion increase cardiac oxygen demand, raise arterial pressure and increase platelet activation and formation of fibrin, all of which are pathogenic processes. Two broad areas of risk are thus immediately introduced. Cardiac stress induced by greater oxygen requirement and raised arterial pressure may result in myocardial ischaemia or infarction, and/or left ventricular strain. Associated dysrhythmias may progress to ventricular fibrillation and cardiac arrest. On the other hand the vascular stress induced by elevated pressure, plus increased clotting activity, together increase risk of cerebrovascular accident (stroke) by haemorrhage or infarction. Myocardial infarction, ventricular dysrhythmia and stroke are the commonest causes of sudden death (Lovallo 1997); these risks are magnified in individuals with pre-existing atherosclerosis, that is the presence of arterial plaque, particularly in the coronary and cerebral vessels.

Though Selye's response based approach was an important breakthrough in the development of stress models, its emphasis on the non-specificity of the response led to criticism and challenge. These fall into two areas: first, research after Selye and Cannon indicates that responses are in fact stimulus specific rather than generalised. Swanson (1991) proposes a biochemical switching hypothesis whereby different kinds of stress may elicit differential production of neurotransmitters, resulting in adaptation specific to the particular stress involved - for example anxiety and fear appear to provoke adrenaline release, while anger and aggression are associated with noradrenaline release. Secondly, the notion of generalised adaptation makes little allowance for any individual elements, such as cognitive variables, which might temper and vary stress response in individuals. Selye defined stress as a nonspecific response to a demand made on the body. Though psychological stress can be mapped onto the GAS pattern, psychosocial elements cannot be fully incorporated. The GAS show how we respond to psychological stress, but perhaps not why. Nevertheless it remains a useful model to illustrate a number of physically stressful experiences, for instance strong physical exertion, or exposure to extreme temperatures.

#### 3:3 The stimulus based approach

Conversely, stress may be viewed as an external stimulus - that is as the independent rather than the dependent variable. This perspective takes a stimulus based approach, suggesting that stress exists as environmental factors which impinge on the individual, rather than as a response within the individual. Also known as the engineering model, this approach sees that external factors result in strain, or stress - that is, stress is something that happens *to* rather than *within* the person. Derived from Hooke's Law of Elasticity, the stimulus-based model does have parallels with Selye's response-based model in that both consider stress as tolerable up to a certain point, beyond which collapse or breaking will occur. The Social Readjustment Rating Scale (SRRS or Life Events scale - Holmes & Rahe 1967) is an example of this approach. The premise of the scale is that life events create stress by necessitating adaptation to change, and it is the degree of adjustment necessitated by such change which is important. The studies underpinning the SRRS involved the linking of stressful events with health records in the ensuing nine months. Holmes and Rahe then developed a numerical weighting for a number of events; cumulative scores indicate susceptibility to physical and psychiatric illness. The difficulties in assigning weight to such personal events mean that the SRRS is not considered an entirely reliable predictive instrument, but it does offer a useful and quick gauge for the amount of stress an individual may be exposed to. In a development of this approach Masuda & Holmes (1967) devised an index of Life Change Units (LCUs) engendered by life events, and suggested that the probability of emotional disturbance increased with the number of LCUs.

The stimulus-based model has flaws: significant life changes may be external stressors but they produce different amounts of stress for different individuals. Such an approach to stress is inherently objective and therefore leaves gaps in the area of individual or personal experience. Yet useful frameworks have been developed on the back of stimulus based ideas. Rahe (1974) proposed the transmission of external stressors via a path of perceptual lenses or filters: factors such as past experiences, physiological responses and learned behaviours may strengthen or weaken the impact of the stressor on each individual. Similar constructs have been described by Dohrenwend & Dohrenwend (1979) and Elliot & Eisdorfer (1982).

The more recent "Hassles versus Uplifts" approach (Lazarus et al. 1981, 1984b, Kanner et al. 1981) has some similarity to the SRRS but considers instead more everyday events which may act as external stressors. Here, though, the element of appraisal – discussed below in relation to the transactional approach to stress – enters the equation. Daily hassles are less dramatic than major life events, but happen more frequently and thus may be more regular sources of stress than the pivotal events itemised in the SRRS.

Both the Life Events and the Hassles and Uplifts scales were developed to allow consideration of the association between stress and ill health, and both have been widely used to explain or even predict stress-related illness (Delongis et al. 1982, Kanner et al. 1981.) The relationship tends to be treated now not as simple cause and effect; rather life events, or "hassles", may be considered as triggers or exacerbating factors which reduce tolerance to a range of illnesses.

#### <u>3:4 The transactional approach</u>

A transactional approach to stress combines aspects of the first two models, in particular the notion of mediators; it evolved as an expansion of the stimulus-based approach. The transactional perspective sees stress in terms of interaction between person and environment. Here subjectivity becomes important; the potentially stressful incident is cognitively appraised by the individual with factors such as experience, personality, available support and relative importance entering the equation. This appraisal process results in perceived demand set against perceived coping ability: where the former outweighs the latter stress will be experienced. Reversal of the equation means stress will be minimal or absent. The all-important factor is individual perception of circumstances - an aspect not fully considered by a wholly response-based or stimulus-based approach.

Lazarus adopted such an approach in the "stress and coping" model (Lazarus 1966, Lazarus 1981, Lazarus & Folkman 1984). This proposes a primary appraisal of the situation, where events are classified as "irrelevant", "relevant and positive", or "relevant and negative" - in other words threat to the individual is assessed. "Relevant and negative" constitutes a stressful appraisal. Secondary appraisal of the event involves evaluation of the options for coping with presumed threat, where the individual considers the potential problem and follows this with a judgment about his or her capacity to deal with it. In essence there is a dynamic relationship between demands and resources which may be altered at any time as a result of some significant event.

This appraisal system furnishes an explanation for individual differences in experience of stress. Experiences, memories, personalities, perceptions of support and of the significance of events vary tremendously and alter overall meaning for each person. The lone parent accompanying a child to hospital during a first, unheralded asthma attack may experience far more stress than the supported parent whose child has suffered and recovered from numerous similar attacks; by the same token personal injury or illness (ranked sixth on the SRRS) will engender different levels of stress for different patients depending on the layers of meaning attached at cognitive appraisal. Lazarus (1999) uses the term "relational meaning" to describe the combination of subjective appraisal and personal significance of a situation.

Yet the stress and coping model too has weaknesses, principally its failure to attend to physiological response to stress. Also the use of the term coping has been criticised: though it is undoubtedly of importance in the appraisal process, "coping" is so integral to human activity that it is hard to see how it is specific to the stress process (Bartlett 1998). Scherer (1995, cited in Bartlett 1998) has queried the approach taken by Lazarus in relation to the involvement of the unconscious in the appraisal process. Lazarus (1999) has answered criticism by enlarging upon the different ways stress might be appraised. He maintains that there can be conscious, intentional appraisal, where information is sifted through, so to speak, in a search for a coping strategy. Secondly Lazarus describes the rapid, almost instantaneous appraisal which can arise from a previously encountered situation. Here there is no deliberate evaluation, and the cues required to provoke response are minimal; Lazarus (1999, p83) still uses the term "short-circuiting of threat". He also continues to draw on Freudian ideas of the unconscious, whereby certain ego defence mechanisms, such as denial or reaction formation, may induce a (psychoanalytically speaking) unconscious appraisal of events. This differs from the rapid "unconscious" appraisal which occurs as a result of intuition. Lazarus (1999) agrees that teasing out the inattentive unconscious appraisal from the ego defence related unconscious appraisal can be a difficult task.

Lazarus's transactional theory of stress, and his discussions of appraisal, certainly make some sense of individual differences in response to stress. If one subscribes to the theories of psychoanalysis then the notion of unconscious appraisal resulting from defence mechanisms may also be acceptable within this perspective. However Lazarus (1999) also maintains that ego-defence "distorts" the individual's appraisal of a transaction, thereby presenting a false picture to anyone attempting to assess that individual. The other way of viewing this however is to accept that, if ego defence mechanisms exist, then they are an integral part of our makeup and are as much a part of our individual response to stress as any other aspect of transaction. This would mean that when we are assessing an individual's response to stress, "what we see is what we get" - in other words this is not distortion, this is the realistic state.

More recent, though still under the umbrella of transactional approaches, is the development of a cognitive phenomenological perspective to explain stress. This suggests that emotion and cognition are so dependent on personal experience that their mediating role is best understood using a phenomenologically-based approach. Further reasons for involving phenomenology include the importance of motivation of the individual in his or her response to stress (Pervin 1989, Cantor et al. 1991) and also the influence his or her "world view" has on assignment of meaning within the transaction ( Scheier & Carver 1987, Janoff Bulman 1989, Wortman et al. 1992). Pervin assigns importance to goal directedness in the shaping of behaviour, and therefore of our reactions to stress, while Cantor's work has examined the way in which goals might structure our experience of life and consequently the manner in which stress is perceived.

World view - the individual's attitudes and beliefs about the world - is perhaps as much a generalisation as the term "coping", already criticised for its lack of specificity. It stands to reason that an individual's beliefs and ways of thinking might have some bearing on response to stress. Fisher (1984) suggests the importance of cognitive processes, in that interpretation of the situation may be the key to explaining different levels of reported stress. The

discrepancy between reality and the individual's goals determines the amount of stress perceived; if "reality" is seen as catastrophic and the victim's goals or ambitions are relatively high then stress will be perceived as high. Conversely lower ambition paired with a more phlegmatic view may mean lower perceived stress. This notion of discrepancy between perceptions of reality and desired goals or ambitions is examined further in discussion of the results of this study.

In a similar vein Janoff Bulman (1989) describes the "assumptive world" in which we live, whereby each individual has a set of schemata, developed as life passes, which furnishes us with the information by which we function on a day to day basis. The cognitive phenomenological perspective proposes then that individual differences in world view account for the wide variety of reactions to apparently similar stressful experiences. The mental constructs which make up the "assumptive world" become particularly vulnerable in the event of extreme stress, as will be seen in the discussion of post traumatic stress in Chapter Four.

#### 3:5 Control as a mediating factor

It is clear that stress is open to quite different interpretations. It can be seen in terms of the physiological implications described by Cannon and Selye, or as a collection of environmental and sociological agents which disrupt normal function. According to the transactional approach, which, essentially, attaches weight to psychological factors, appraisal and world view are the important issues in perception and experience of stress.

In addition to change, the sense of helplessness and loss of control engendered by stressful situations appear to result in certain stress-related physiological and psychological effects which influence both health and emotional status (Rotter 1966, Stewart & Salt 1981, Fisher 1984); certainly the transactional model places emphasis on perceived control as a determinant of experienced stress. Sudden death in humans, related to unmitigated and uncontrollable

stress, has been described in various studies (Engel 1971, Mittelman et al. 1995). Such dramatic outcomes may be relatively rare; nevertheless perceived lack of control over aversive and stressful situations has distressing effects. Animal psychology experiments have generated a number of, admittedly controversial, findings in the field. Brady et al. (1958) examined the effects of uncontrollable stress on rhesus monkey pairs, subjected to intermittent electric shocks. Both monkeys had access to a pressable bar: the "executive" could thereby postpone shock while the yoked monkey's efforts had no effect. At post mortem the executive subjects exhibited severe peptic ulceration while the yoked monkeys had sustained a significantly lower amount of physiological damage. These findings were at the time extrapolated to human behaviour and an apparent link with stress in business executives. The Brady experiment appears to contradict the notion of a link between greater loss of control and greater stress - though it emerged on close examination of the methodology that the more nervous or active monkeys had been assigned to executive roles, thus the yoked monkeys were very possibly more placid, introducing the confounding question of temperament and its link with stress.

The role of chronic bacterial infection by helicobacter pylori in human peptic ulceration has been accepted widely, but there is still thought to be a persisting link with stress. Somewhat different is the type of ulceration which results from the acute physiological stress which occurs in the critically ill. Acute, stress-induced ulcers may appear in the fundus and body of the stomach in patients with septicaemia, trauma or severe burns. The mechanism whereby these develop is poorly understood though hypovolaemia and ischaemia are thought to lead to necrotic damage to the mucosa (Harrison 1991). Potential stress ulceration tends to be routinely managed in the ICU by administration of antacids, which elevate the pH of the gastric contents thus reducing acidic damage. H2 blockers are also used - these block the histamine receptors since it is thought that histamine stimulates gastric secretion of acid (Harrison 1991).

Control as an explanatory variable in stress response has been linked to health by many researchers. Wallston et al. (1978) built upon the Internal:External (Locus of Control) scale (Rotter 1966) by including specific health items to develop the Multidimensional Health Locus of Control Scale (MHLC). This identified three dimensions - internal, external and "powerful others" loci of control, where "powerful others" implied that health, or the course of an illness, was in the hands of professionals rather than controlled either by the individual or by fate. In some ways control over health and illness-related matters differs from expectancy of control over life events in general. Some researchers have suggested that an internal locus of control is desirable since it acts as a buffer against stress in ill health (Cohen & Edwards 1989, Hurrell & Murphy 1991). Yet illness may be one of the situations in which an external locus of control protects against stress, in that the sick patient can yield himself or herself up to the health professionals and place much of the effort and worry in their hands. Certainly Folkman (1984) has remarked that it is not always necessarily maladaptive to adopt an external locus of control. And it must be remembered that though a degree of control may be feasible in many illnesses, in the context of intensive care control becomes a fairly distant possibility, certainly during the period of acute illness, when by the very nature of the critical condition all possible support is needed. For the patient in the ICU control is at best minimal, indeed is likely to be virtually absent at times. We can dress up the situation and as the patient's faculties return offer things like patient controlled analgesia pumps, but in reality much of the control over the situation is given up to the health professionals.

Predictability - or lack of it - of an aversive event is closely linked to controllability, and this aspect was introduced to the stress debate by Weiss (1970). Predictability of shock was manipulated among three groups of rats: received shock randomly, received shock with warning, and no-shock controls. Here peptic ulceration arose in 100%, 67% and 25% respectively, accompanied by highest corticosteroid release, core temperature and weight loss in the unpredictably/randomly shocked group. The conclusion here was that predictability could modify response to equal doses of stress, despite the absence of control. The

introduction of controllability of shock, by using executive: yoked pairs, resulted in far greater ulceration in the yoked rats, the reverse of Brady's findings. Here the element of control appeared to lend a buffering effect (Weiss 1971a).

Further aspects of uncontrollable stress have been explored in experimentally induced states of learned helplessness (Seligman et al. 1971). In this series of experiments dogs which were subjected to unavoidable painful electric shocks in a pre-test situation were unable to learn avoidance behaviour when the shocks were administered in a shuttle box which allowed escape. Control and avoidance groups from the pre-test situation learned quickly to jump the barrier in the shuttle box and escape shock. Seligman reported marked behavioural and emotional changes in dogs from the experimental group - the animals were generally anxious and fearful, and when subjected to shock in the shuttle box exhibited apathy and prostration. The conclusion was that learned helplessness develops when outcome is not contingent on performance, and this learned behaviour is then generalised to other aversive situations where avoidance is in fact possible.

Extrapolation of findings from animal psychology is of course questionable, yet effects similar to those noted by researchers like Brady, Weiss and Seligman have been demonstrated in human subjects. The ability to predict stressful events may reduce emotional disturbance, and studies in clinical settings have borne this out (Siegel & Peterson 1980, Taylor 1984). Peterson & Seligman (1984), examining risk factors for depression, argued the importance of perceived control in the onset of depression; if an individual perceives, rightly or wrongly, hopelessness or lack of control in the face of stressful or aversive situations then he or she will learn helplessness. Control-related aspects of stress in the ICU patient are considered later on in this chapter in section 3:7.

#### 3:6 Social support as a mediating factor

The role played by social support systems in moderating the stress engendered by difficult or traumatic situations has been widely investigated and for the most part it has been found to act as a buffering agent (Cobb 1976, Cohen & Wills 1985). Social support may be broadly defined as a measure of the number and the quality of social relationships in which the individual is involved (Bartlett 1998) Individual perception is important, in keeping with the premise of the transactional model of stress, and thus a level of social support which is optimal for one person may be wrong for another, either in amount or style.

Brown & Harris (1978) postulated two explanatory mechanisms - the direct effect on wellbeing, plus the buffering effect on the impact of stress on health. They concluded, from a study of women experiencing distressing life events, that threatening or stressful events were associated with depression, and that depression was much more likely to arise if no close confiding relationship was available. Gottlieb (1985) suggested that perception of strong social support might increase ability to deal with stress by reducing the appraised level of threat, while Oatley (1988) linked social support and stressful life events by proposing that social roles and self worth are diminished by stressful events. While the supported individual cam begin to reconstruct a sense of self worth with the help of social networks, the unsupported individual is less fortunate and the life event may prove detrimental to his or her mental health.

Yet it must be allowed that for some individuals, who perceive themselves to have a surfeit of social support, there may in fact be a deleterious effect on mental health, with consequent negative consequences and increased stress (Sandler & Barrera 1984, Coyne & Downey 1991). One of the earliest studies of social support and its influence on health was the examination of suicide by Durkheim (1951) who suggested that either extreme - social isolation, or alternatively a high density social network - might increase the risk of suicide in susceptible individuals.

Stansfield et al. (1998) have examined social support in relation to psychiatric morbidity, as measured by the General Health Questionnaire 30-item test. They identified three areas of support: confiding support, practical support and negative aspects of close supportive relationships. Risk factors for psychological distress emerged as different between the sexes, with social support predicting better mental health in men, and the negative aspects of close supportive relationships predicting poor mental health in both men and women.

The complex nature of stress and the daunting amount of literature in this vast area mean that a degree of selection is unavoidable in its discussion. Many different situations may be perceived as stressful - loss, isolation, pain, moves and changes - and the variables which influence individual perception are diverse. It is beyond the scope of this work to discuss at length all the risks and imponderables involved. However the study centres on an attempt to make sense of one particularly difficult and very often unavoidable stressful event, namely critical illness requiring ICU admission. The stress specific to this event is considered in the following section.

#### 3:7 Stress in the ICU patient.

The fundamental importance of change and lack of predictability as sources of stress have been discussed above. Where then does this leave the ICU patient, subjected to all manner of stressful events, all engendering change, the majority unpredicted, and many allowing the minimum of perceived control? Though clearly a sense of perspective must be retained where ICU stress is concerned, there are undoubtedly some unique elements to intensive care which mean these patients' experiences will be differently, if not necessarily more, stressful than those of patient groups in other areas of the hospital.

Stress experienced by ICU patients is multifaceted and may be produced by such factors as pain, fear, social isolation and immobility, helplessness and ineffective communication - all

- . .

over and above the generalised debilitation associated with critical illness. The days of heavy sedation and induced paralysis for all ventilated patients are long gone, and the introduction of increasingly sophisticated and sensitive ventilators which complement rather than simply replace the patient's own respiratory effort has revolutionised the management of a large proportion of the critically ill. Thus patients may well be at least semi-conscious of events - and it will be seen that even those apparently unconscious have the potential to report distress following the experience.

Lovallo remarks that

"Capture and the helplessness associated with forced immobility are known to be among the most profound of aversive stressors."

Lovallo W. (1997 p62.)

Intensive care admission may not constitute capture, but a degree of immobility is certainly an unavoidable feature of highly monitored care involving ventilation tubing, nasogastric tubes, urinary catheters, intravenous, intra-arterial and intracranial cannulae, and electrocardiogram (ECG) leads. Like the unfortunate Lemuel Gulliver, who awoke to find himself not only nursing a hangover but also tethered and in pain, ICU patients may experience frightening and painful stimuli yet be too confused or ill to understand what is happening. The treatments and procedures attendant upon ICU admission have been compared to torture in the context of ICU syndrome (Dyer 1995). This collection of symptoms - hallucination, delusions, confusion and subsequent depression - has been mentioned in the literature review in Chapter Two in relation to sensory disturbance. ICU patients are deprived of meaningful sensory input yet are simultaneously exposed to a battery of strange, uninterpretable stimuli leading to sensory imbalance (Kleck 1984). The patient in the ICU is in the unenviable position of suffering from both over and underload - double jeopardy in the stress stakes.

Sensory overload, or overstimulation, occurs as a result of bombardment by higher than normal levels of stimulation, often in more than one modality (Goldberger 1986). Often too the stimuli are sudden and unpredictable. Potential sensory overload in the ICU is produced by such things as the unfamiliar noise and activity, the repetitious sounds of ventilators and the chirruping of infusion pumps. Exposure to noise in excess of seventy decibels has been reported in the past (Bently et al. 1977); the recommended limits now are forty five decibels in the daytime, twenty at night. Stimulation by way of treatment procedures may feel sudden and unpredicted to the patient despite the best efforts of staff to prepare and inform. Endotracheal suction, insertion or removal of lines, chest X-ray, physiotherapy and general nursing care - all these are unfamiliar sensations which may happen frequently and are potential stressors. In conjunction with this sensory overload, sleep disruption may compound all the other stressful factors impinging on the ICU patient. It is worth noting here that post traumatic stress - a major area of interest within this study - has also been associated with sleep disorder (Frank et al. 1988, Ross 1989) - a link which is explored in the following chapter.

Sensory deprivation - defined as a drastic reduction in the level and variability of a person's normal stimulation from, and intercourse with his environment - may present further problems. In this instance the patient is deprived of acceptable or chosen stimuli. Though stimuli may be raining in on the patient by way of noise, painful sensation and unfamiliar handling , what may be missing from the experience is the ability to move at will, to communicate with others, even properly to see other people. Goldberger (1986) suggests that in experimental situations, the major sources of stress in a state of sensory deprivation arise from confinement, social isolation and immobility. One further stimulus missing for the ICU patient may be comforting human touch, though this is simpler to remedy than some of the other sensory deficiencies. Integral now to the approach to caring in the ICU is the encouragement of physical touch as a comfort measure and not simply as a component of interventions or procedures. If the habits and wishes of the patient can be elicited so much the better, and family and friends may be apprised of this need in the patient.

Communication within the ICU has been a well researched area and the important effect of good communication on patient wellbeing is widely acknowledged (Ashworth 1980, 1990 Turnock 1989, Calne 1994). Our communicative abilities are largely derived from our ability to receive sensory stimuli, yet as has been seen this process is disrupted for the ICU patient. Senses are dulled both by disease processes and by the drugs administered as part of treatment. Swollen eyes, blurred vision and impaired hearing are common. As discussed earlier, communication coming from the patient is seriously disrupted by the fact that the endotracheal tube - via which assisted ventilation occurs - passes through the larynx, temporarily rendering the individual voiceless. ICU staff are well versed in methods of eliciting conscious intubated patients' wishes - using alphabet and picture boards, sign language and lip reading. Nevertheless, to be unable to articulate pain or fear, or level of comfort, is a frightening and frustrating situation to be in when one is physically well; for the critically ill individual the stress is compounded. Being intubated and unable to talk have been reported by recovering cardiac ICU patients as significantly more stressful than other aversive events within ICU (Pennock et al. 1994).

ICU designs vary with age and purpose, but most have single rooms as well as a multi-bedded area. Single rooms in hospital can sound like an attractive concept, but for the critically ill patient they may increase stress in relation to communication. Social isolation for unlimited periods is a distressing experience (Argyle 1972) and perceived isolation is a problem which has been reported by ICU survivors (Daffurn et al. 1994, Dyer 1995). Very often the patient is nursed in a position not conducive to eye contact, and despite the constant presence of at least one member of staff, a strong sense of abandonment and seclusion may be felt.

Control, or lack of it, is not a precise stress variable in relation to health and illness. Some see strong value attached to control over our bodies (Angell 1985, Brownell 1991) while for others reduced control may be acceptable and even preferable during illness, indeed attempts to retain control may be detrimental to wellbeing (Reid 1984). In relation to chronic illness, perceived control has been found to diminish stress and to relate to positive mood and greater psychosocial adjustment (Affleck et al. 1987, Taylor et al. 1991). However the chronic illnesses considered - such conditions as diabetes mellitus, acquired immunodeficiency syndrome (AIDS) and chronic renal failure - differ from many of the acute and critical conditions cared for in ICU. Reid (1984) examined the importance attached to control in relation to disease severity and found that surrendering control was deemed to be beneficial psychologically, rather than attempting to shoulder the burden of control for critical illness.

The purpose of the ICU is to restore failing organ function and integrity, and thus by the nature of their severely ill condition ICU patients have lost independence, while their powers of control over, and prediction of events are markedly diminished. If, as has been suggested by researchers such as Angell (1985) and Brownell (1991), control and predictability are important factors in the mediation and perception of stress, then ICU patients set out at a disadvantage. Add to this state the aversive events inherent in treatment, and the potential for distress becomes clearly visible, indeed the ICU patient's situation has been described as :

"a cocktail of psychological helplessness, physical debility due to severe illness, anxiety and depression."

Jones & O'Donnell 1994 p90

Lack of control, passivity, difficulty in communicating, a sense of being "trapped": all these factors may contribute to a belief in these patients that control over events has become impossible. This may be generalised once transfer out of ICU has been effected, when the patient may have no impetus to exert control in situations where control is in fact possible. Over and above the stress engendered within the ICU is the strong potential for the development of a degree of learned helplessness. The uncontrollability of events and the inability to control outcome may lead to learned helplessness during initial recovery,

accompanied by low self-esteem and psychological dysfunction (Abramson et al. 1978), two of the areas assessed in this study. Lazure (1997) suggests that loss of control is a major contributor to the helplessness experienced by ICU patients; other researchers have described the learned state of helplessness which becomes apparent as recovering patients are transferred out of ICU to the general ward, and, similarly, the psychological dependence displayed after discharge home (Benzer 1983, Jones & O'Donnell 1994).

It is possible to explain stress for the ICU patient using any one of the three described models of stress. The response based approach of the GAS may still be applied in the case of extreme physical stress. If one were to look solely at the stress arising as a result of acute illness then the GAS might be mapped almost directly onto the illness trajectory. However the absence of a substantial cognitive component in the GAS limits its usefulness in a study of intensive care psychology.

It could be argued too that a stimulus based approach is useful in considering the stress of ICU admission, as any number of external stimuli - noise, pain, the alien environment, constantly changing faces of staff - can be seen to impinge on the patient. The bombardment of the senses is one of the striking features of the ICU and probably affects everyone - patients, relatives and staff - at the first encounter. The noise, sights and smells can be quite dizzying, and are things which still strike the author sometimes on entering new and unfamiliar units. The stimulus based model of stress could actually be extremely useful if one were taking a helicopter view of the ICU in order to audit potential stressors. Yet the common criticism of such models endures: that is that they are inherently objective or prescriptive. Thus in a study such as this, where patients' perceptions of their own psychological wellbeing are the principal interest, the stimulus based approach is probably too narrow.

Appraisal or perception of the stressful situation is the underlying principle of the transactional approach. Though patients might have been admitted to ICU with the same illness, stayed on

the unit for the same length of time, and had similar levels of social support, their perceptions of the experience may vary quite markedly. The different perceptions of demand - the trappings of critical illness and ICU admission - versus ability to cope, could result in a different psychological outcome for each individual. This is the premise underpinning the research problem: since psychological wellbeing after the event is perceived so differently by patients, what aspects of the experience is it contingent upon?

Critical illness and ICU admission are, happily, the experience of a minority, and the extraordinary procedures and life saving measures experienced by these patients have been described in Chapter One. Some of these events may be considered so uniquely stressful that they fall outside the bounds of everyday experience. It can be argued that the ICU experience is one which has the potential to provoke post-traumatic stress, and discussion of this specific stress syndrome is the basis of the following chapter.

#### CHAPTER FOUR. POST TRAUMATIC STRESS

"... any unusual smell, even a sudden strong scent of flowers in a garden, was enough to send me trembling ..... the sound of a car backfiring would send me flat on my face, or running for cover."

Robert Graves 1929 p220

For many people the response to a stressful event will be relatively mild; the less fortunate may suffer a more sustained, painful reaction. Post traumatic stress disorder (PTSD) is a long term consequence of an acutely stressful and traumatic experience, and its defining feature is the development of characteristic symptoms after an overwhelming event. These symptoms fall into three main clusters: the first are symptoms associated with intrusive thought and reliving of the trauma, the second with avoidance, where the sufferer tries to minimise exposure to reminders, and the third cluster relates to hyperarousal - that is symptoms such as hypervigilance, increased startle response and insomnia (DSM IV American Psychiatric Association 1994). In addition emotions such as anger, sadness, shame or guilt may be reported (Brewin et al. 1996), often depending on the nature of the traumatic event preceding the syndrome.

#### 4:1 Recognition of the syndrome.

The combination of psychological symptoms found in PTSD became a recognised diagnosis in the early 1980s, though the consequences of traumatic stress have been described in different populations from a much earlier period. Military personnel in particular have presented with the clusters of symptoms now recognised as PTSD: American Civil War veterans suffered from "nostalgia" and "irritable heart" (Da Costa's syndrome); survivors of trench warfare in World War I, and veterans of warfare since have demonstrated the ways in which mental disorder may follow physical shock in combat. Terms such as "shell shock", "battle" or "combat fatigue", "war neurosis", "soldiers' neurotic illness", have all been applied to warrelated traumatic stress responses (Connor & Davidson 1997). Veterans of the Vietnam war in particular became a rich source of information about PTSD, information which has been seen as lending some validity to an experience formerly treated in a dismissive manner (Fairbank et al. 1983, Davidson et al. 1990, Keane & Kaloupek 1997).

Prior to the so-called "introduction" of the diagnosis in the latter half of this century, there had been a tendency to label the complex of symptoms as an illness or abnormality within the sufferer. Psychiatrists in hospitals in Britain, many unfamiliar with front line conditions, treated traumatised soldiers from World War I for hysteria or neurotic breakdown (Gersons & Carlier 1992); it has been suggested that this "illness" label allowed justification of the massive fallout rate of conscripts, thus suppressing any need to admit to the horrors of war (Stone 1985).

PTSD in civilian life is also described. Grief responses in survivors of the Boston night-club fire - a study produced by Lindemann (1944) - included a mix of psychological symptoms including visual and auditory hallucinations, aggressive behaviour, and other disorders which indicated considerable emotional disturbance in those observed. The Lindemann study is one of the earlier examinations of this cocktail of psychological disorders in survivors of nonmilitary trauma, and further it demonstrated the beneficial effects of reinstigating the grief process in survivors - that is, encouraging thoughts and memories of the incident in order to promote some sense of control.

Lessons learned by psychiatrists in the armed services have been translated to psychiatric care in civilian populations. The syndrome has been observed following natural disaster (McFarlane 1988), in emergency service personnel (Hytten & Hasle 1989) and of course in survivors of physical trauma sustained in accidents (Mayou et al. 1993, Blanchard et al. 1995). The actual symptoms determined by the Diagnostic & Statistical Manual IV (American Psychiatric Association 1994) and used as diagnostic criteria, are reproduced in the following table.

#### Table 4a: Post traumatic stress disorder - DSM IV diagnostic criteria.

# Exposure to a traumatic event in which the following were present: (i) the person has experienced, witnessed or been confronted with events involving actual or threatened death or serious injury, or threat to physical integrity of self or others. (ii) the person's response involved intense fear, horror or helplessness.

### 2. Persistent *reexperience* of the traumatic event including one or more of the following sensations:

(i) recurrent, distressing and intrusive recollections of the event.

(ii) recurrent distressing dreams about the event.

(iii) sense of reliving the event or dissociative flashbacks.

(iv) distressing psychological reaction to cues resembling an aspect of the event.

(v) physiological reaction to such cues.

# 3. Persistent *avoidance* of stimuli associated with the event, and numbing of responsiveness since the trauma was experienced, including three or more of the following:

(i) effort to avoid thoughts, feelings or conversation associated with the event.

(ii) effort to avoid people or places which may induce recollection.

(iii) inability to recall important aspects of the event.

(iv) reduced interest or participation in significant activities.

(v) sense of detachment or estrangement from others.

(vi) restricted range of affect.

(vii) sense of foreshortened future.

# 4. Persistent symptoms of *increased arousal* since the event, including two or more of the following:

(i) difficulty falling or staying asleep.

(ii) irritability or angry outbursts.

(iii) difficulty concentrating.

(iv) hypervigilance.

(v) exaggerated startle response.

5. Duration of symptoms (as outlined in 2,3,4 above) exceeds one month.

## 6. Disturbance results in clinically significant distress or dysfunction in important areas such as social or occupational sphere.

PTSD may be acute - if the duration of symptoms is less than 3 months, or chronic - if duration of symptoms is 3 months or more. Delayed onset PTSD may occur, where symptoms do not appear until at least 6 months or more after the traumatic event.

#### DSM-IV American Psychiatric Association 1994 (309.81)

Clearly this is an uncomfortable state to endure. Physiological as well as psychological symptoms may be present. Some of the symptoms can be understood in the context of the stress response, discussed in detail in the previous chapter, and helpful in understanding PTSD. The symptoms of anxiety and hyperarousal, such as increased muscle tension, heightened alertness, sleep disturbance, hypervigilance, indicate a prolonged state of stress resistance, fuelled by continued outpouring of stress hormones. Lovallo (1997) remarks that the central nervous system mechanisms which integrate the physiological stress response may be subject to long term changes in cases of PTSD, as a result of alteration in connections between frontal lobe and limbic system , and in the feedback loop described in Section 3:2 in the previous chapter.

#### 4:2 Biology of PTSD.

A specific biology of PTSD has emerged over the last ten years - from the late 1980s onwards - and this is now a burgeoning area of research whose findings help to make some sense of the symptoms described by sufferers. The biology of PTSD seems to differ from that of stress, and the biological abnormalities which have been detected in PTSD go some way towards refuting the view that this is not a bona fide syndrome, or that it is a purely neurotic disorder. Cortisol releasing factor (CRF) is produced in increased amounts as of course is cortisol, and increased negative feedback on the hypothalamic-pituitary-adrenal axis is reported (Pitman 1997). It has been suggested that CRF may directly produce some symptoms, since it appears to enhance neurotransmission in the locus coeruleus - the structure either side of the brain stem whose cells are involved in active or rapid eye movement sleep (REMS) (McGough 1992). This enhanced neurotransmission may account in part for the vivid dreaming reported by PTSD sufferers. The locus coeruleus contains noradrenaline receptors thought to be involved in REMS: their activation increases REMS and destruction suppresses it (Harrison 1991), further support for the possible link between outpouring of catecholamines and disrupted sleep and dreams. Also in relation to neurotransmission, Pitman (1997) reports a decrease in serotonin uptake in sufferers with possible consequences for mood and emotional lability.

Other findings include evidence that enhanced memory associated with emotional arousal may occur as a result of activation of the adrenergic - that is the stress hormone release - system. Neurochemical research on animal subjects has demonstrated increased storage of emotional memory as a result of infusion of noradrenaline (McGough & Gold 1989). Hagh-Shenas et al. (1999) describe noradrenaline's interference with memory storage and the apparent inverted U- shaped relationship of the two. That is, at very low and very high levels of noradrenaline release, memory storage is affected. Hagh-Shenas suggests that excessive noradrenaline release at and around the time of the trauma may be instrumental in forming excessive sensitivity to trauma-related information.

In addition to the activation of adrenergic receptors, further influence on the memory system may be effected by increased circulating cortisol, which is excitatory to the hippocampus. In situations of stress, raised levels of circulating cortisol may saturate neuroreceptors in the hippocampus thereby interfering with neuronal activity and memory formation (Cahill et al. 1994, Hagh-Shenas et al. 1999). Such findings do suggest that memory for emotional events may be modulated in some way by activation of the stress response.

#### 4:3 Conceptual models

Like most psychological phenomena, PTSD can be viewed from a number of perspectives, in addition to the biological perspective detailed above. A variety of conceptual models exists to

furnish explanations of the specific symptoms. Keane et al. (1985) have adopted a behavioural approach to assessing and treating PTSD, and explain its development by way of both classical and operant conditioning. The fear response, which will include hyperarousal and may be followed by flashbacks and intrusive thought, will rarely be evoked by the original conditioned stimulus - for example the sound of gunfire or shelling - once the victim has been removed from the war situation. However, stimulus generalisation means that similar stimuli experienced in civilian life may evoke the same response. Loud noise, for example that produced by fireworks or machinery, may be near enough to the noise of gunfire to evoke symptoms in sufferers, as in the quote from Graves' autobiography at the head of this chapter.

To use some non-military examples of classical conditioning in relation to stress after a traumatic experience, an antiseptic odour, originally encountered in hospital paired with some extremely painful or unpleasant unconditioned stimulus, can produce a hyperarousal response when encountered by some individuals. Thus a previously neutral stimulus such as the smell of a skin cleaning solution becomes associated with activation of the autonomic nervous system and an adrenaline evoked response. In another example, migraine sufferers may develop a conditioned response to the prodromal symptoms of their headaches - for instance an odd taste, or dizziness (Sarafino 1990). Similar situations have been observed in patients receiving chemotherapy, for whom the odour, the colour and even the sounds associated with preparation of a drug solution may become a conditioned stimulus evoking a nauseous response (Morrow & Dobkin 1988, Kvale et al. 1991).

In this manner classical conditioning may play a part in demonstration of PTSD symptoms; equally, operant conditioning may take effect. Traumatic and distressing experiences are inherently aversive, and the majority of us would not wish to repeat them given a choice. Keane et al. (1985) suggest that the avoidance behaviour adopted by PTSD sufferers is explained simply by way of negative reinforcement. That is, repeated avoidance of situations,

conversations and the like will prevent the unpleasantness of remembering and reliving events.

Yet as with most behavioural psychology when applied to human behaviour, gaps appear when higher order thinking - motivation, attribution, direction - is considered. Similarly the biological or neuropsychological approach offers rational and appealing explanations - for instance the notion of enhanced neurotransmission in the locus coeruleus contributing to vivid dreams and nightmares - but it does not deal fully with the immense range of responses to trauma. Just as the General Adaptation Syndrome (Selye 1956) does not account for individual cognitive appraisal in its explanation of stress, so biological models of PTSD, though compelling, leave gaps where cognitive components are concerned.

Cognitive appraisal models (Janoff Bulman 1985, 1989, Epstein 1990) view PTSD as a result of the disruption of assumptive constructs. Strongly held beliefs in the world, which are summarised by Janoff Bulman (1985) as our notions that the world is comprehensible and controllable, benevolent in the main, and that each individual is worthy and largely invulnerable, are shattered by the experience of a threatening event. The more devastating the damage to schemata, that is the more incongruent the trauma-related information with preexisting ideas about life, the more work required to repair and reconstruct. As Wortman (1992) describes:

"Events that can be incorporated into a person's view of the world may cause little disequilibrium and resultant distress; those that shatter a person's view of the world may cause intense distress and result in subsequent health problems."

Wortman 1992 p229.

Lazarus (1999), whose transactional approach to stress (Lazarus & Folkman 1984) is outlined in Chapter Three, also subscribes to this view by way of his notion of stress appraisal. He suggests that as a result of trauma, crucial meanings may have been undermined - that is, the sufferer's fundamental reasons for living may have been actually damaged, rather than merely challenged as in "common or garden" stress.

Janoff Bulman's version of our fundamental assumptions - in particular the notion of a benevolent and meaningful world (Janoff Bulman 1989) - does raise the question of cultural specificity and world view. De Silva (1999) suggests that although this might be a view commonly held in Western cultures, very different fundamental beliefs may be held across the world by people in cultures where, say, war and conflict prevail or where natural disasters are frequent. Religion too probably shapes schemata to some degree. If this is the case, then responses to trauma ought to differ vastly across different areas. This is a just criticism of the "shattered assumptive constructs" of Janoff Bulman, a criticism which has been answered in part by studies of the effects of traumatic events on members of different cultural groups.

Symptoms of PTSD have been described in American soldiers after Vietnam (Frye & Stockton 1982, Keane & Kaloupek 1997), in Sri Lankan soldiers fighting the Tamil separatists (De Silva 1995) and in Israeli soldiers involved in Middle East conflict (Solomon et al. 1987). Ethnic differences within armies have certainly been found in relation to incidence of PTSD (Williams 1950, Kulka et al. 1991), but the general response to trauma seems to be similar in the parts of the world which have been studied. Of course it may be that response to traumatic events is different in some very small remote communities, and this is sure to be a point of interest as research into cultural aspects expands.

The immense cognitive mismatches induced by a traumatic event activate intense and overwhelming emotions; these mismatches must be processed by way of assimilation and accommodation. Resick & Schnicke (1993) suggest that maladaptive assimilation and overaccommodation can occur, whereby the individual suffers from distorted thinking patterns and exaggerated changes to pre-existing schemata. However it must be remembered that the

events witnessed or experienced by sufferers may have been so intensely distressing and traumatic that these are not distorted cognitions, in fact they are, sadly, more realistic than those which were held before the event occurred.

Control has been seen already to play a part in perception of stress (see Chapter Three), and the degree of uncontrollability or unpredictability of aversive events may be involved in the aetiology of PTSD. Highly uncontrollable traumas have great potential to induce this shattering of mental constructs. Foa et al. (1989) have related the emergence of PTSD in torture victims to the uncontrollability and unpredictability of the stressors involved. According to this cognitive appraisal model, PTSD is the evidence of maladaptive coping with the new constructs enforced by overwhelming events. Attempts to assimilate the alien information associated with the traumatic event may, for some, result in the symptoms described, such as the increased level of arousal, flashbacks, attempts at avoidance and a range of negative emotions.

Also in a largely cognitive mould Horowitz (1973,1976,1979) has described an information processing model, one which underpins the structure of the Impact of Event Scale used in this study. The model was also fundamental to development of the DSM criteria reproduced above. Emphasis in the Horowitz model is placed on processing of incoming information, and on cognitive theories of emotion; traumatic events involve massive amounts of internal and external information, most of which cannot be matched with current schemata since by their nature they are outside the realms of normal experience. Major elements of the Horowitz model include:-

- Information overload a situation occurs where new information ideas and images cannot be processed.
- Incomplete information processing the new information is only partially processed and therefore remains in an "active form of memory" although out of conscious awareness.

• "Completion tendency" - the information must be processed repeatedly until reality and cognitive models match.

Horowitz (1974) focuses on the meaning of the traumatic event in the context of pre-existing assumptions and life plans: how shattering is the overturning of these assumptions, and how large the discrepancy in world view before and after the event? He proposes a five stage cognitive model, where the reactions to extreme stress are observed as:-

- Crying out or alternatively a completely stunned response
- Avoidance denial and numbing
- Oscillation denial alternated with intrusion
- Transition attempts to process information
- Integration processing is completed

It is suggested that unprocessed information is shunted out of awareness and stays in an undigested state. However the completion tendency (which has parallels in the "repetition compulsion" encountered in psychoanalysis) requires repeated attempts to process the raw data, thus traumatic information breaks through repeatedly, as evidenced by reports of intrusive, uncontrollable thoughts and vivid flashbacks or nightmares. Denial is used by sufferers as the chief defence mechanism to avoid overload, hence the symptoms of avoidance. Symptoms continue until the raw information has been fully dealt with. Intrusive thought facilitates information processing, while avoidance and denial potentially allow gradual assimilation of the experience. Once processed, the information is no longer stored as "active" memory. Horowitz (1979) proposes that treatment be directed towards aiding completion of processing - not necessarily to the pre-trauma state, more likely to a significantly shifted "world view".

This view of PTSD, which considers that trauma related material remains active in the memory until processing is complete, is supported by research studies into memory and trauma. Foa & Kozak (1986) suggested the possible formation of fear networks within the memory, built around information involving both the original trauma stimulus, and the physiological and cognitive reactions to the event. Reminders of the event trigger these fear networks leading to intrusive thought, while attempts to suppress the memories manifest themselves as the symptoms of avoidance reported by sufferers.

McNally et al. (1995) have shown that Vietnam veterans suffering from PTSD have a tendency to recall more trauma related memories than any other autobiographical memories, when compared with veterans with no PTSD. Others have administered an emotion-based version of the Stroop test (Stroop 1935) and have demonstrated an interference effect when words with specific emotional impact are presented to PTSD sufferers (Foa et al. 1991, Hagh-Shenas et al. 1999).

The information processing model also has some parallels in the psychoanalytic approach to trauma, inasmuch as it considers psychic equilibrium to have been disturbed by overstimulation. Symptoms persist until equilibrium is regained. Freud (1919) viewed military trauma through a psychodynamic lens, proposing that trauma to the psyche was a result of overexcitation of the individual's drives. He shared the notion of those who succeeded him, that traumatic neurosis had different properties to other neuroses and took a longer time to process or resolve. Of traumatic neuroses such as those arising after wartime experience, or railway collisions, he said:

"The traumatic neuroses give a clear indication that a fixation to the moment of the traumatic accident lies at their root. These patients regularly repeat the traumatic situation in their dreams ..... it is as though these patients had not finished with the traumatic situation, as though they were still faced by it as an immediate task which has not been dealt with."

Freud 1916/17 pp314-5

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Later, Freud described the negative effects of attempts to "blow away" the consequences of distressing events, remarking that the endeavour to "undo" a traumatic experience was directly implicated in the formation of symptoms of neurosis. (Freud 1925). Krystal (1968) adopted a similar approach to Freud in examination of post-traumatic stress in holocaust survivors, citing the importance of drives. However the emphasis in both Freud's, and later Krystal's ideas was on individual disposition and pre-trauma conflicts rather than on the stressful experience itself.

Taking a wider yet still essentially psychoanalytic view, Grubrich-Simitis (1987) has considered the weight of stressors alongside the constitution of sufferers. These stressors may include:-

- Disruption from family and usual environment
- Separation anxiety rekindling of anxieties and emotions experienced in infancy at separation from a target attachment figure
- Helplessness and anticipation of own death
- Annihilation of individuality
- Elimination of privacy
- Debasement and degradation
- Witnessing of atrocities helplessness and horror arises not only from the individual's experience but from the observation of others
- Barbaric reinfantilisation as a result of traumatic stress, primitive phantasies, and anxieties from the pre-Oedipal period, may be reactivated

It does not take a huge mental leap to translate some or all of these stressors to situations endured by some patients in the ICU, though of course there is normally no malevolent intent, and in the main staff strive to optimise wellbeing and reduce stress for patients. Separation anxiety occurs in those close to the critically ill patient, as a manifestation of loss - the natural and overwhelming fear in this situation is that the much loved individual may die. Yet separation anxiety may also occur in the sick patient who either recovers, or never loses, consciousness. Attachment figures may well appear to be lost to the patient, particularly when visiting is intermittent, analgesic drugs are causing confusion, and constant treatments or procedures are disrupting the patient's and relative's time together. The potential problem of social isolation has been mentioned earlier and it is feasible that placing the patient in a single room may exacerbate any separation anxiety.

The above are all situations which result in the demands of the id, or primary needs, becoming paramount once more, and Grubrich-Simitis (1987) warns of the potential "structural damage" to the psyche as a result. This damage may manifest itself in overuse of denial, escape into memory and fantasy, constant alertness, impaired interpersonal functioning and avoidance of cathexis to new, yet maintenance of cathexis to lost objects: in other words, the distressing symptoms observed in PTSD sufferers described in Freudian terms.

Further psychoanalytic comment is offered by Wilson (1980) who has examined PTSD in Vietnam veterans, a heavily researched group in this context. This research supported the ideas of Erikson (1968) who considered his fifth psychosocial crisis stage - "identity versus confusion" - to be crucial in the formation of a sense of self, and the fostering of psychic wellbeing. Wilson's subjects, who like many of the young U.S. soldiers sent to Vietnam were likely to be in this fifth stage, demonstrated the disruptive effect on the mind of exposure to extreme trauma. Many were left foundering in the sixth psychosocial stage - "intimacy versus isolation" - and suffered crippling post-war psychological problems. Wilson's research can be used to account for many of the observations made of PTSD victims and for the apparent disintegration of their psyches.

Finally, the concept of PTSD has been placed in a psychosocial framework where individual variables such as previous experience, pre-existing psychopathology, coping capacities, age and education are considered alongside situational variables like the location of the original

trauma and its familiarity or strangeness, and the recovery environment which includes social support and cultural attitudes towards the experience (Green et al. 1985). These various aspects have been used to seek variables which might predict the direction of outcome following a traumatic event. Green describes two broad outcomes - either personal growth and restabilisation, that is non-pathological integration of the experience, or alternatively a pathological outcome in the form of PTSD development.

Research by Wilson & Krauss (1985) has detected a negative correlation between social support and symptom severity, a positive correlation between degree of stress and symptom severity, but little association between pre-morbid personality and the development of PTSD. This refutes early psychoanalytic ideas that individual constitution is the main determinant of response. The best predicting variables in Wilson's study were found to be the severity of the stressor, and the degree of psychosocial isolation of the recovery environment.

As stated already, post traumatic stress may be a normal reaction to an abnormal event. Neal et al. (1997) have estimated the lifetime prevalence of PTSD as 8%. Yet not everyone develops symptoms despite exposure to events which fulfil the DSM criteria outlined above. The DSM list of features represents the prevailing opinion of experts who subscribe to the whole idea of PTSD and believe there is enough evidence to describe a syndrome, although it may not arise in everyone exposed to traumatic stress. The World Health Organisation International Classification of Diseases (ICD) also recognises PTSD, but while agreeing with the symptoms of re-experiencing of the trauma, via intrusive recollection, it does not consider numbing or avoidance as essential for diagnosis (WHO:ICD-10, 1992). The DSM-IV also included Acute Stress Disorder (ASD) as a newly classified disorder (DSM-IV, F 43.0) where the pattern of symptoms is very similar to PTSD, but arises and then resolves within four weeks of the original traumatic event.

Some though have opposed the concept of post-traumatic stress as a discrete disorder and have suggested instead that it may be a by-product of a stress conscious society, or worse a factitious disorder - where the "sick role" is adopted for its own sake - or malingering state where there is a clear secondary gain. This may be financial gain, the avoidance of legal action or the obtaining of addictive drugs (Peterson et al. 1991). Such a suggestion is not new - "compensation neurosis" was described in the last century as the rate of reported invalidism rose following a change in the compensation laws for rail accidents.

The existence of a more stress conscious society does not, however, mean that the acknowledgement of a stress syndrome is mistaken or has merely been dictated by fashion. There is much evidence - examples of which are quoted within this chapter - of a particular mix of signs and symptoms arising in people exposed to traumatic or threatening events. Peterson at al. (1991) are correct in outlining the motives of some apparent sufferers, but faking or exaggerating illness is hardly a new idea. Malingerers can present with any number of symptoms, but this does not negate the existence of their chosen condition. For the purposes of this research, PTSD is accepted as a potential and very feasible response to overwhelming traumatic events, a response which represents, according to Turnbull (1997):-

"an unveiling of a normal survival instinct in exposed individuals"

### Turnbull 1997, p19

Yet to subscribe to the theory is to accept the broad premise that the response is not the abnormal factor but rather the preceding event which evoked it. The literature suggests that post traumatic stress is experienced by ordinary people who have experienced an extraordinary event. One perspective in particular can be linked with post traumatic stress in ICU survivors, that is the notion of a shattering of constructs or world view, as proposed by researchers like Janoff Bulman and Horowitz. Except for the few cases where patients are undergoing

readmission to the ICU, for very many patients admission and treatment will be cognitively disruptive in the extreme and have the potential to be very stressful. The information processing model may throw light on the experiences of these surviving patients.

The nature of the stressor involved in PTSD development can vary tremendously but to reiterate, the DSM-IV criteria include the proviso that it must be psychologically distressing and outside the realms of usual human experience. In its purest sense trauma means life or death experience, and though intensive care admission and treatment are not the same as torture, natural disaster, military combat or rape, what they can and do involve are dislocation from a familiar environment, pain and loss of control, a threat to physical integrity and a sense of threat to one's life. This is not a slight on ICU staff, it is a realistic look at the experience of the critically ill patient.

Brewin et al. (1996) have noted that despite the comprehensive nature of Horowitz's theory of stress response and the development of PTSD, he does not deal in depth with apparent differences in response to similarly traumatic events, and individual interpretations and outcomes are perhaps not fully explained. Indeed, predicting variables in relation to PTSD have rarely been sought out; yet this element of prediction is of great importance in this study, where the relationship between ICU events and reported symptoms of PTSD - as measured by the IOES - is to be examined. If exposure to the same events does not automatically lead to the same responses, is this exclusively because of individual patient differences or are there other predicting variables which can be teased out? Can psychological vulnerability following critical illness be foreseen? As discussed in the introduction, individual personalities cannot realistically be assessed prior to admission, without the ability to forecast which individuals will become ill. But even acknowledging the existence of inherent differences, there are enough events occurring to warrant examination of factors extraneous to personality/nature which may be involved. The IOES is considered to be a valid instrument which identifies the symptoms of post traumatic stress - development and validation of the scale is discussed in

detail in Chapter Six - and it may be that this study will demonstrate that the condition can occur in some measure in discharged ICU patients.

## **CHAPTER FIVE. QUALITY OF LIFE**

"Health is the gift of the body, and patience in sickness the gift of the minde: then who will say that patience is as good a happinesse as health, when wee must be extremely miserable to purchase this happiness."

from "Paradoxes and problemes" John Donne 1633

## 5:1 The concept of health related quality of life.

Within our health care system the question "Is life worth living?" has provoked much argument and observation - principally from those who think it is not. As pioneering treatments have been developed to combat previously fatal conditions - transplantation for organ failure, cytotoxic drugs for carcinomas, heroic reconstructive surgery - so has interest in the price paid in terms of quality of life. The importance of medical markers such as five year survival figures or remission rates is not disputed, but it has became apparent that there is an extra dimension to be considered. Furthermore, disease does not have to be life threatening to reduce quality of life; some chronic diseases such as rheumatoid arthritis or inflammatory bowel disease may cause more pain, more reduced function and more psychological upset than many potentially fatal conditions like cancers or cardiac disease.

Living with a chronic disease and enduring its treatment, or - more pertinent to this study surviving an acute episode of severe illness, extends beyond the purely physiological. What matters and may be more meaningful to the individual is the impact of a specific health problem on the nature, or quality, of his or her daily life.

However, like stress, the term "quality of life" has become something of a catchphrase, and it is now at risk of becoming a vogue outcome variable in health service research. It may no longer be the "missing measurement" in the field of health care (Fallowfield 1990) but it could perhaps be described as one of the most misinterpreted. Increased interest in both holistic care and treatment outcomes has resulted in any amount of peripheral data being linked to quality of life. At the same time, pharmaceutical companies and health promotion campaigns have taken to including the term within their advertising, widening its application still further. This study deals specifically with intensive care psychology but could be subsumed under this umbrella term "quality of life". The aim of this chapter is to examine the concept of quality of life and outline the various methods of measuring it, before moving to consider the quality of life following ICU admission for critical illness.

Increased interest in quality of life has been accompanied by a growing difference of opinion as to what the term actually represents. No doubt life quality has always been of importance to those whose health is in some way compromised, and to their families. Few of us would wish immobility, pain or social incapacity upon ourselves - where health and wellbeing are concerned we are all fairly hedonistic.

Yet defining or describing health related quality of life absolutely is fraught with problems since this is an abstract concept, and the lack of consensus hampers attempts at measurement. So much depends on the personal value individuals attach to health status. "Quality" derives from the Latin "qualis", meaning "what sort", and the sort of life which is considered acceptable for one person may be unacceptable, undesirable or simply unattainable for another. However there is a growing consensus that quality of life is a multidimensional concept which incorporates three broad areas or domains - physical, psychological and social functioning (Aaronson et al. 1987, Siegrist & Junge 1989, Mead et al. 1994). These relate to the World Health Organisation's much quoted view of health as a state of mental, social and physical wellbeing, not merely absence of disease (World Health Organisation 1947). Quality of life has been described as:-

"A complex amalgam of satisfactory functioning in essentially four primary domains .... psychological, sociological, occupational and physical."

### Fallowfield 1990 p19

The mix of factors within these domains varies according to the research perspective. Some theorists discriminate between psychological factors - Walker & Assher (1986) suggest six components of quality of life: physical, cognitive, affective, social, economic and ego function factors (PCASEE). Other models sub-divide the physical aspects -the EuroQol descriptive system for instance addresses mobility, self-care, pain and ability to perform usual activities as separate dimensions alongside mental health. Wellbeing is a term much used in the context of quality of life. Diener (1984) has divided wellbeing into the two components of life satisfaction, that is cognitive evaluation of life status, and affective wellbeing, referring to the balance of negative and positive affect in the individual's life.

## 5:2 Measuring health-related quality of life.

Health related quality of life can be viewed from different perspectives depending on the relative weight researchers attach to outcomes. There is the standpoint of the economists, justifiably concerned about the vast amounts of money ploughed into health care. Though cost analysis is not the rationale for this study, the expense of intensive care is acknowledged as a matter of concern to everyone involved in ICU outcome research. The costs incurred by these patients are staggeringly high: one recent UK cost-utility analysis of intensive care estimated total hospital cost per "Quality adjusted life year" (QALY) at £7500 (Ridley et al. 1994).

Alternatively there is the approach adopted by this thesis - that is, what overall impact do health care interventions and treatments have on people's lives? What quality of life is

afforded to survivors by the miracles of modern intensive care? Certainly lives are saved in the ICU, but are we resurrecting some patients only to abandon them to a convalescent period marked by anxiety and mental strain?

The effects of health care can be measured in a variety of ways. The most stark is probably by recording the opposing outcome variables of death or survival. It is not an exaggeration to say that for some practitioners in the past, particularly those zealously involved in research, mortality data have sufficed as an outcome measurement. Yet present day survival rates are impressively high - it is estimated that only around 5% of all medical intervention results in death (Dolan 1994). So what happens to the surviving 95%? How do health care and medical intervention affect their lifestyles - what "sort" of life will they enjoy?

Many disease-specific outcome measures exist - variables such as exercise capacity following cardiac surgery, readmission rates for parasuicides, or extended life expectancy resulting from organ transplantation. Indicators like these are of course of major consequence, but they tend to reflect a solely medical model - that is one constructed on the presence or absence of signs and symptoms of disease. There is another range of variables which can be measured to give a more complete picture of the outcome of health care intervention. These variables are concerned with issues like satisfaction and dissatisfaction, anxiety levels, self-esteem and social functioning - psychosocial as opposed to physiological measures.

Applying quantitative approaches to psychological matters has always been controversial, and attempts to assess quality of life illustrate the difficulties involved. It is important to acknowledge that, like so many psychological frameworks, quality of life is a hypothetical construct. Quality of life and perceived wellbeing depend to a great extent on individual experience, expectation and desires. The psychological and social domains are relatively abstract areas, and even physical functioning retains many subjective qualities despite being the most straightforward domain to assess. Certainly the degree of contentment or misery experienced by groups of patients cannot be observed or measured directly. It is necessary therefore to resort to less direct measures in order to represent the information and quantify quality of life.

Although quality of life is concerned with subjective phenomena its measurement has been frequently performed using quantitative approaches based upon the methodology of psychometric research. These have given rise to a number of different ways of examining and measuring quality of life.

Clinician-rated instruments:-

Though quality of life would appear to be concerned with the patient's interpretation of health outcomes, a number of measures exist which depend on the practitioner's objective assessment of a patient's quality of life. The Karnofsky Performance Index (Karnofsky & Burchenal 1949) for instance centres on physical activity and dependency levels. Patients are assigned to its categories by the health practitioner, but categories do not take into account the different amount of social support, for example, which may be available. Thus an immobile patient will always score higher than a mobile one, despite possibly having better support at home. More recent practitioner-assessed instruments exist, many developed as an offshoot of rapidly evolving cancer treatments. The Spitzer Quality of Life index (Spitzer et al. 1981) assesses a wider range of functions by including social support and outlook on life alongside physical factors.

Though scales involving clinicians' rating of quality of life are useful and do have predictive value (Morris 1986), their fundamental flaw is their lack of representation of the patient's subjective view. They cannot fully describe something so unquestionably and intrinsically personal as quality of life. This is borne out by studies analysing the relationship between patients' and practitioners' ratings on the same scales, in which discrepancies in the ratings

suggested that health related quality of life cannot be assessed adequately by practitioners on behalf of patients (Evans 1984), indeed clinicians may underestimate quite considerably the quality of life a patient is experiencing (Slevin et al. 1988).

### Self-rating instruments:-

Measurement of subjective phenomena requires participation of the subject, and this requirement is met by self-assessment quality of life instruments. These take the form of questionnaires or scales, for completion by the patient, which measure aspects of the three inter-related domains - physical, psychological and social functioning. Self-rating instruments constitute a large group of quality of life measures. Some will be administered in the hospital or clinic, others completed at home or even over the telephone. They may be generic or disease-specific, aimed at a broad picture of quality of life or at narrower targets like social networks or mental wellbeing, scoring methods may vary - but their common objective is to measure the patient's own perception and evaluation of function and wellbeing.

Broad measures of quality of life include such widely used tests as the Sickness Impact Profile (Deyo et al. 1983) and the Nottingham Health Profile (Hunt & McEwan 1980). These require responses to statements about perceived state of health and wellbeing across a range of dimensions including mobility, work, social life, sex life and emotions. Both the SIP and the NHP were developed, in the United States and the United Kingdom respectively, as measures of sickness-related dysfunction rather than as indicators of disease. In contrast the General Health Questionnaire (Goldberg 1978), one of the assessments used in this study, contains items relating to general health, social function and psychological wellbeing, and aims to screen for psychological dysfunction. This instrument is discussed in more depth in Chapter Six.

All three can be described as self-assessed, broad measures of health status or quality of life, yet their approaches are quite different. A vast range of self-rating instruments now exists; there are scales which will measure depression and anxiety (Zigmond & Snaith 1983), cancer-specific quality of life (Selby et al. 1984) or the incidence and nature of pain (Melzack & Torgerson 1971) - all under the umbrella of health-related quality of life. In addition to these are the various self-concept and self-esteem scales which are of particular relevance in assessment of mental wellbeing. Modification and development of existing quality of life instruments have increased the pool of measures still further, although the field of targeted measures for specific diseases remains comparatively small.

While the current strong interest in health-related quality of life is generally welcome, the gathering of unlimited amounts of non-clinical data in an increasing number of self-rating instruments may not be, since there is the possible risk that too great a volume of data may lead to misinterpretation and misapplication of findings. O'Boyle (1995) expresses the problem concisely as a need to "ensure that the measurable does not drive out the important".

A criticism sometimes levelled at self-rating instruments is their subjectivity. It has been suggested that personality traits, or factors such as pain threshold and tolerance, compromise the validity of these measures (Ware 1984). It is hard to imagine how these factors could not bias response, indeed as they are integral to our individual experiences of life and health they probably allow a very accurate picture of quality of life to emerge. As such, the subjectivity and personalisation of self-rating instruments may be their strength. It may be argued then that self-rating instruments produce a more accurate representation of quality of life than clinician-rated instruments.

Further criticism comes from Bowling (1991) who, though recognising the importance of patient self assessment, argues that the lack of any items addressing perceived improvement is

a weakness in many self rating scales since this leaves an important aspect - patient recovery - unmeasured.

Even self-rating scales impose their own construction of quality of life on respondents and leave gaps in the information: complex psychological and social matters such as coping styles, life events and the interrelationships of patient, family and health practitioners may be missed, all of which contribute to quality of life. Assessment of these factors either requires instruments involving hundreds of items, or the use of a qualitative research approach. Most qualitative methodology approaches the research problem by way of case studies or interviews, transcribed verbatim and analysed phenomenologically (Polit & Hungler 1993, Lapierre et al. 1997, Petrie et al. 1999). In the case of quality of life, for example, qualitative analysis might yield underlying themes explaining what really constitutes life quality for a group of subjects, and what the modulating factors are (Pope & Mays 1995, Horn & Munafo 1997).

A qualitative approach might seem ideal for quality of life, in that it could explain individual attributions of meaning to life (Mead et al. 1994). The qualitative research interview can offer detailed information about the research participant's perception and understanding of a situation (King 1994). Certainly a qualitative approach with ICU survivors might address some of the problems of description and categorisation, though it must be reiterated that much of the <u>initial</u> interest in quality of life was generated by researchers looking for evidence that some lives may not be worth living, militating against any attempt to appreciate individual experiences.

Qualitative approaches have been used to study patient psychology in acute situations: Tanner et al. (1993) have examined the meaning of illness experience in the acutely ill, while the experiences of ICU patients have been described by examination of thinking processes at different levels of consciousness (Lusardi & Schwartz-Barcott 1996) and by analysis of narrative data from surviving patients (Hall-Smith et al. 1997). Such studies make valuable contributions to the overall picture of the ICU experience but tend towards smaller sample size - for example the study by Lusardi & Schwartz-Barcott observed only nine patients in depth, and that by Hall-Smith et al. twenty-six.

A qualitative approach was not a consideration for this particular study; the combination of psychometric assessments was chosen for its ability to generate a useful mix of data from a relatively large group of subjects, data which could then be submitted to standard quantitative analysis. Nevertheless the importance and relevance of qualitative approaches to quality of life research are acknowledged though further discussion is beyond the scope of this piece of work.

Cost-utility approach to quality of life:-

As the purchaser-provider division in the Health Service has become more explicit, both groups have realised the need to focus on the effectiveness and quality of the care provided. The consequence has been a burgeoning interest in the outcomes of treatment, and health-related quality of life is increasingly being used as an indicator or measure. The cost-utility approach, which requires a common measurement of outcome, relates quality of life to financial input in an attempt to prioritise spending.

This is arguably justifiable in the area of intensive care, since cost effectiveness is important where resources are scarce, and the ICU is fast becoming the most crowded hospital department, with insufficient beds to meet either acute or elective requirements (ICNARC 1994, Mason 1995, Ryan 1996). Those who are forced to make decisions regarding admission to ICU and treatment - or withdrawal of it - therein, are faced with hard choices where value judgments are unavoidable. Reliable information which might inform strategic decisions is presumably to be welcomed.

The use of Quality Adjusted Life Years - QALYs - goes some way towards addressing this conflict of infinite demand for finite resources by assigning numerical values to health states in order to calculate the cost-effectiveness of lives. The pioneering work on this scoring system was undertaken in the United States (Rosser & Watts 1971); more recently the Oregon project combined the QALY concept with cost data (Kaplan & Bush 1982). The aim of this particular project was to prioritise conditions requiring medical treatment with a view to allocating funds accordingly - namely, health care rationing. Here in the United Kingdom the QALY system has attracted interest despite concern over the original methodology (Hunter 1993) and the Department of Health Economics at York University has undertaken research into priority setting according to cost per QALY of health care interventions. This has allowed the construction of league tables where health care interventions are ranked by QALY value (Williams 1985).

The working principle of the QALY is that one year of healthy life expectancy is worth one. The value falls as quality of life decreases, thus a year of unhealthy life expectancy is worth less than one, and being dead is calculated at zero. Since quality of life can be considered so poor as to be worse than death, it is possible for a QALY to have a negative value. On this basis, a beneficial health care activity or treatment is one which will generate a positive amount of QALYs, while an efficient treatment is one where the cost per QALY is as low as possible.

The immense costs incurred by ICU patients were mentioned at the outset of this chapter, with an approximate total hospital cost per QALY of £7500, as estimated by Ridley et al. (1994). This figure resulted from a combination of individual costs with significant decreases in quality of life perceived by surviving patients - measured in this instance by cognitive abilities, ability to work and social factors. The study brought the enormous expense of intensive care into sharp focus: clearly if expenditure on non-survivors were to be added to the QALY calculation the cost of intensive care would increase still further.

Although QALYs might aid the distribution of limited resources, they have been criticised as discriminatory and subjective (Rawles 1990). Calculations of health years derive from <u>healthy</u> subjects' evaluations of factors such as mobility, ability to work and freedom from pain. Yet QALYs are generic measures and consequently their coverage is restricted. The assumption made by QALYs is of course that information generated is applicable universally - an approach which disregards the evaluation and undermines the autonomy of the individual patient (Goodinson & Singleton 1989).

The enormous demand for ICU beds, and the costs involved in their provision, is acknowledged by the author who spent a number of years involved in both implicit and explicit rationing of intensive care services. When the ICU is frantically busy and finances are stretched to their limits, naturally the premise of the QALY might seem a rational answer to an overarching problem. To what, however, should the numerical values be assigned? Factors which have been evaluated by proxy as essential to good quality of life may bear little relation to those which emerge as important in the patient's experience. To date, bad dreams, hyperarousal, and lowered self esteem do not feature in the calculation of the QALY.

On a more prosaic level, the process of costing the QALY to assess efficiency becomes quite intricate in the context of intensive care. The patient's condition may involve complex pathologies which require a variety of interventions over and above basic respiratory support, and there is no doubt that the QALYs generated for ICU patients are high cost. In this confusing situation it is less likely that the QALY would be used in deciding how to treat an individual patient, and much more likely that it could be used to generalise about which groups are treated.

If, as suggested by proponents like Maynard (1987) and Williams (1985, 1992), a utilitarian argument is adopted then a great deal of intensive care provision might disappear, in order to minimise costs and maximise benefits for all. Williams (1985) has suggested that those

procedures which produce a greater number of QALYs relative to cost ought to take precedence over those where QALYs are fewer and costs greater. For example a hip replacement (normally no intensive care requirement) might take priority over a coronary artery bypass graft for moderate vessel disease (usually some intensive care required immediately post-operatively). In fairness Williams does not rule out a need for intensive care altogether, since heart valve replacement is included in the examples of procedures considered to be relatively cost efficient (Williams 1985). Yet directly comparing the lifesaving properties of intensive care with the quality of life enhancing properties of, say, a knee or hip replacement, is misleading - almost like comparing two maps drawn to different scales. There is a danger that potential ICU patients would rarely be prioritised on this cost benefit principle, and many viable patients may lose altogether the chance of survival.

One further, and very important point, is raised by Smith (1995) who comments on the possible effect on pioneering work within intensive care. It is indeed the case that many interventions now carried out in a relatively straightforward manner, with minimal if any ICU requirements - for instance coronary artery bypass grafting or renal transplantation - began life as complex and unwieldy procedures with a high intensive care input.

#### 5:3 Predictive scoring in the ICU

Over the last fifteen to twenty years scoring systems have been developed as an aid to predicting outcome in patients admitted to the ICU. Scoring systems are severity of disease classification systems, initially developed to aid the management of severe illness - for example as research instruments in treatment comparison studies, or for triage purposes. Intensive care and mechanical ventilation can sustain life in the most deeply damaged patients who may or may not regain consciousness - both represent tremendous achievement by the practitioners and innovators involved. Yet intensive care suffers the same fate as other areas of healthcare, that is an ever increasing demand for its limited resources. Defining those most likely to benefit is difficult since response to disease is highly individualised, evolving technology and drug therapy alter the picture constantly, and ultimate quality of life must be considered. Hence the introduction of scoring systems in an attempt to aid decision making.

Some scoring systems measure illness severity directly by assigning points according to the degree of derangement of certain physiological variables - items such as arterial and venous pressures, blood gases and urine output. Additional scoring is made for variables such as age, depth of coma, and underlying chronic disease. Such systems include the Acute Physiology and Chronic Health Evaluation - the APACHE II (Knaus, Draper et al. 1985) and APACHE III (Knaus et al. 1991), or the Simplified Acute Physiology Score or SAP (Le Gall et al. 1984). Degree of overall physiological derangement at any one point is expressed by way of the total score.

Other systems measure illness severity indirectly by assessing consumption of resources - bed occupation and ICU workload - and calculating scores accordingly. Examples include the Therapeutic Intervention Score or TISS (Cullen et al. 1974) and the Nurse Dependency Score (ICS 1983).

For the greater part, high scores indicate increasing severity of illness, thus it is possible to calculate estimates of mortality for groups. However summed scores are too narrow a measure to allow mortality prediction for individual patients; models have evolved which have greater power to predict individual patient outcome. Such predictive models work by combining the illness severity score with coefficients based on some additional variable - for example the underlying disease (APACHE III) or the number of organs which have failed (Organ Failure Score - Chang et al. 1988). Once the admission severity score has been allocated, the chances of survival may be calculated. In the case of APACHE III the equation is produced with the help of a database containing a massive number of ICU profiles, each

comprising clinical assessment, physiological measurement and ultimate outcome data. If APACHE produces a fairly low figure - say 25 - then the patient has a 25% chance of dying in the ICU. A high figure such as 90 indicates only a 10% chance of surviving the admission. Changes in magnitude and direction of the assigned figure allow prediction of outcome.

Scoring systems thus allow:-

- A prognostic indicator in patients with clearly defined diagnoses.
- Comparison of treatment regimes.
- Clinical audit.
- Efficiency comparison between hospitals.
- Rationalisation of an expensive healthcare commodity.

Severity scoring and prediction systems such as APACHE III have as their strength precise and accurate databases which are not subject to the optimism and pessimism of the ICU clinicians. They quantify the degree of physiological derangement, thereby indicating a likely prognosis, and can be useful instruments to aid clinical judgment. Yet it is this very objectivity which constitutes one major criticism - does intensive care management require something more than mathematical equations and probabilities? Where do intangible aspects like the clinician's wisdom or the patient's disposition fit? Though many practitioners are happy to use scoring systems as a tool, they would see them as an adjunct to rather than a substitute for clinical acumen. Further, the majority of the scoring systems tend to concentrate on physical survival, paying scant attention to patient psychology. The revised APACHE III system has been marketed as a tool for assessing quality of life alongside the original APACHE outcome measures, but some practitioners' clinical experience suggests this may be an over-optimistic approach (Vassar & Holcroft 1994). Scoring ICU patients on a physiological basis in the first instance is probably a practical and a not unreasonable practice; the ICU can be a busy and disorientating place in which to instigate as well as receive treatment, and guidelines can be very welcome to busy staff. What might usefully expand the prediction, however, might be data relating to the potential for disruption of psychological recovery. There may be factors which can be tacked on to physiological scoring systems in order to effect some kind of psychological triage system, aimed at improvement of outcome rather than at rationalisation of the service. That is, the information on risk of psychological problems would be utilised post-discharge in order to enhance the patient's follow-up care.

#### 5:4 Quality of life after ICU

As discussed in Chapter One, ICU therapy and nursing care are aimed at stabilising disease processes, and returning the patient to the best functional capacity possible. The issues of quality of life and wellbeing become complicated in the aftermath of all the intensive therapy directed at the critically ill patient. The very nature of critical illness means that things like mobility, and levels of pain or discomfort, are likely to be reported as worse than usual, particularly in the early weeks after discharge. One might expect answers to questions asked by generic quality of life measures to demonstrate a degree of deterioration from normal. Yet if a truly holistic approach is to be adopted in measuring ICU outcomes, the quality of life of individual survivors is an essential consideration. Relying on instinct alone to guess at psychological outcome may be as reactionary as it would be in relation to physiological outcome.

A particular aim of this study was to measure emotional or psychological facets of quality of life following critical illness, in order to reveal specific points about psychological recovery. An individual's physiological status probably has a major influence upon wellbeing, but as the literature regarding measurement has illustrated, there is not necessarily a perfect positive correlation. Despite good functional status, psychological wellbeing may be slow to return. Anecdotal and some empirical evidence (Bergbom-Engberg 1988, Dyer 1995, Topf et al. 1996) suggest that perceptions and expectations vary greatly among ICU survivors, allowing considerable scope for the examination and measurement of individual psychological outcomes.

Methodology for examining quality of life after intensive care, though certainly beyond its infancy, is still relatively young. Long term survival and quality of life have been addressed in relation to the immense financial input in intensive care (Rustom & Daly 1993), and in terms of return to work or restriction of daily activities (Mulcahy et al. 1993). Aspects of economic productivity by way of functioning in paid employment are often addressed in quality of life studies: in this study many of the research subjects would not be expected to be back at full time work during the follow-up period, and in addition a fair number were retired . Aspects such as ability to perform tasks and activities are measured by the GHQ28, while some of the ego-related needs commonly met by work - self-worth, self-esteem, sense of usefulness - are measured by the Rosenberg self esteem scale.

Research using self-rating instruments in the specific context of critical care has been reported: Fridlund et al. (1993) constructed a social functioning scale to measure quality of life in men recovering from myocardial infarction, in a study of the need for social support following discharge from the Coronary Care Unit. Hulsebos et al.(1991) piloted use of the Sickness Impact Profile (SIP) in a retrospective study of ex-ICU patients, concluding that the selfadministered version of the test can be used as a reliable outcome measure. The study does not refer to the SIP's principal disadvantages in this context - namely its length and complexity.

The use of single measures to assess quality of life has been criticised as contributing to the inadequacy of many studies, and the inclusion of more specific instruments alongside the

generic may add meaning and depth to the examination of wellbeing (Aaronson et al. 1989). Information generated needs to be specific to the event if valid and useful conclusions are to be drawn. For example an important social aspect such as self-esteem may need to be addressed alongside the ubiquitous depression and anxiety. Self esteem, the evaluative component of self concept, may be subject to change at various points in life, given its dependence on both internal narcissistic supply and external sources. Fluctuation in self esteem is common in response to illness (Barry 1996); a period of illness can be a considerable threat to self esteem, albeit temporary, when one considers the potential assault on body image, function and sense of self worth. In particular, a severe illness necessitating intensive care and temporary loss of independence may affect self esteem (Halm & Alpen 1993, Kleiber et al. 1994). Although pre-morbid levels cannot easily be measured, it is helpful to consider self esteem as an important component of wellbeing and to include a specific measure. In the same way, psychological phenomena relating specifically to the experience should be measured; in the case of the ICU experience the stress perceived may give rise to symptoms post-discharge. These may be missed or inadequately picked up by a generic measure, and some measure specific to post traumatic stress is indicated. Using a combination of generic and specific measures, the issue of post-ICU psychology can be tapped at several different points. Battery approaches such as this are being used more frequently in the attempt to refine and develop quality of life research (Ussher et al. 1995).

Quality of life for ICU survivors is becoming a significant outcome variable, in pace with so much health research in the 1990s. Psychological and social issues merit serious attention and are now attracting much greater research interest alongside survival and functional capacity. Broadly speaking, research studies which evaluate quality of life following critical illness may have a cost-utility basis (Rustom & Daly 1993, Ridley et al. 1994) or alternatively may be aimed at providing informed and improved after care. The most popular research methods adopted have been personal interview (Le Gall et al. 1982, Bams & Miranda 1985, Patrick et al. 1988, Yinnon et al. 1989) or, as in the present study, postal questionnaires (Maclean 1985,

Mundt et al. 1989, Dragsted 1991, Krikevold et al. 1996). Length of follow-up also varies widely, ranging through three months (Krikevold et al. 1996), one year (Ridley et al. 1994), two years (Miranda & Miranda 1991) to eight years (Yau et al. 1991). Dragsted (1991) examined differences in outcome between the six and twelve month points, reporting improvements for all patients. Another study by Zaren & Hedstrand (1987) reported improvement between six and twelve months for trauma patients only.

Within these studies estimation of quality of life has been by measurement of such diverse variables as physical function (Le Gall et al. 1982, Maclean 1985, Yinnon et al. 1989), emotional wellbeing (Mundt et al. 1989), perceived general health (Loes 1987) and return to employment (Yinnon et al. 1989). Thus it can be seen that comparison across different patient groups and units is problematic. Patrick et al. (1988) have worked to produce a quality of life instrument for intensive care patients, the Perceived Quality of Life Scale (PQOL) which will measure those aspects pertaining specifically to the ICU rather than the general ill population. More recently Jones et al. (1993) have investigated the use of a tailored system to measure changes in health status post-discharge. Though such tools have not been widely used they are likely to warrant further development given the popularity of other disease or condition-specific quality of life measures.

What information has been generated by these follow-up studies? Rustom & Daly (1993), in a United Kingdom based study, assessed quality-of-life after intensive care, finding that 50% of those interviewed admitted to increased anxiety levels post-discharge. The rationale for this particular study was cost-effectiveness, and the researchers looked particularly at the relationship between financial input and survivors' quality of life. Such cost-utility studies are in contrast to this study, where the relationship under scrutiny is that between the stressors within the ICU and ensuing psychological wellbeing.

Other studies have borne out this finding of significant decline in quality of life after intensive care, particularly for trauma victims and younger patients (Ridley & Wallace 1990). Group comparisons have been undertaken, for instance Kleinpell (1991) studied age and sex-related differences in the impact of ICU admission on quality of life at six months post-discharge. Findings demonstrated a greater impact on quality of life for males, but no significant difference between elderly and middle-aged survivors. The number of days in hospital had an inverse relationship to quality of life after discharge. In contrast Tian & Miranda (1995) found age to be a discriminating factor in quality of life follow-up, with older patients reporting decrease in physical function as their most significant problem, whereas for younger age groups dysfunction in the psychosocial domain was the prime concern. Age has also been found to influence perception of vulnerability to serious illness (Leventhal et al. 1985).

In another comparison Brooks et al. (1997) compared the health related quality of life of ICU survivors sixteen months after discharge with that of a community sample, using their own (relatively long) questionnaire. Sixty three percent of the ICU patients reported functional impairment, inability to attain full health and poor quality of life, compared with 29% of the community sample. However, having been a patient in intensive care did not emerge as an important determinant of perceived health-related life quality. Instead items such as pain, relationships, life beliefs, severe depressive symptoms, social function and appearance were the significant determining factors.

Thiagajaran, Taylor et al.(1994) asked surviving trauma victims to compare pre- and posttrauma quality of life and found a 13% decrease in perceived wellbeing, accompanied by modest to severe impairment socially and occupationally for over half the sample. Though many reported changes might be attributable to the effects of multiple trauma itself, all the subjects in these studies had been managed for a substantial period on the ICU, and the influence of this experience on subsequent quality of life outcome must be a consideration. One United Kingdom centre in particular has contributed to the field of ICU psychology through examination of patients' wellbeing following survival. The research team at Whiston Hospital, Merseyside has highlighted some of the long term effects of admission, and reported the advantages of discharge information specific to the ICU, and the offer of further contact via patient support groups (Jones et al. 1994, Jones & O'Donnell 1994). This group of researchers followed survivors for one year and evaluated psychological health using the Profile of Moods States (POMS) questionnaire. Although the percentage of patients reporting high levels of anxiety and depression was quite low, almost half were suffering a degree of anxiety at two and six months post discharge. No relationship between age and scores was found. In addition the benefits of involving relatives in the assessment of quality of life has been demonstrated (Jones et al. 1994). The intensive care research group at Liverpool University continues to study post-discharge wellbeing, and the state they have termed "dyshabilitation" wherein patients report fatigue, depression and anxiety during the recovery period (Jones, Humphris & Griffiths 1998).

Assessment of, and interest in the quality of life of surviving patients is important; what is also of concern is that the information generated is of some use, and can benefit both the patients and (indirectly) the practitioners. Wilson & Cleary (1995) have argued that quality of life data, in order to be meaningful in practice, needs to enhance understanding of causal relationships. This way effective interventions can be devised on the strength of it. This study aims to take surviving patients' wellbeing and life quality into account, by incorporating their views on the outcome of their ICU treatment. It also attempts to fulfil the criterion suggested by Wilson & Cleary (1995), by investigating the relationships between variables associated with the ICU setting, and quality of life-related outcome measures. In revealing factors which might have some bearing on long term psychological wellbeing, it allows the possibility of modulating the effects of these factors.

Hopefully most of what is done to patients in ICU is done with the purpose of making them better, and to suggest that traumatic or unpleasant therapies are omitted or even radically altered for the sake of patient psychology may appear to be an irrational proposition, particularly to the practitioners involved in high-pressure, acute healthcare. Yet if evidence emerges which suggests certain factors compromise psychological wellbeing, perhaps such factors should be considered in case there is any way of buffering their effect. Certainly the idea that staff can develop an awareness of which events and experiences might contribute to impaired long term psychological recovery, and detract from the quality of this restored life, is not unreasonable, and takes the holistic approach to care several steps beyond the hospital doors.

# CHAPTER SIX. ASSESSMENT TOOLS.

In this chapter the rationale for the choice of assessments is discussed, followed by an examination of the development of the three tests chosen.

## 6:1 Rationale for the research methodology

The study was operated on the premise that admission to, and treatment within the ICU has the potential to be a highly stressful experience. In relation to the aspects of stress discussed in Chapter Three, the ICU situation has a number of stressful features:-

- The patients encounter abrupt change, both to their environment and to their self concept.
- The ICU admission interrupts organised life processes and accepted rules of existence.
- The patients are faced with uncertainty and unpredictability about both their future and their overall "world view".

Much of the literature reviewed suggests that patients surviving the stress of ICU admission and treatment may suffer from psychological problems, both short and long term. There may be argument as to how many will experience difficulty: to use just two of the studies cited, Pauser (1984) suggested that a high proportion of patients could be affected while Rowan (1992) found fairly low rates of depression and anxiety, though she did note that social dysfunction was a common problem. The general consensus seems to be that ICU admission and treatment have the potential to disrupt wellbeing and adversely affect quality of life across several domains. Thus a generic measure was deemed necessary, and was the first measure to be considered, before the more specific instruments.

A number of factors led to the choice of the GHQ 28 for the purposes of the study. The questionnaire itself was designed for self-completion and is clear, unambiguous and fairly

short, making it particularly suitable for postal survey. A further advantage of the test's brevity was its suitability for individuals recovering from severe illness: the GHQ 28 was to be administered by post in conjunction with other tests, and it was important not to send an overload of paperwork, to avoid both fatigue in participants and the risk of non-response.

The sub-scales allowed relatively straightforward assessment of four potential problem areas for this group of patients. Although symptoms specific to each individual's condition were likely to be present, at least at first follow-up, those somatic symptoms assessed by the GHQ are very general ones which may also be associated with distress. From clinical experience, and from the information generated by the literature review, it appears that anxiety, social dysfunction and depressive symptoms are all potential problems following discharge from intensive care. Thus the subscales produced by the GHQ28 - somatic symptoms, anxiety, social dysfunction and severe depressive symptoms, had the potential to give a more detailed picture of psychological dysfunction.

The GHQ 28 concentrates on breakdown in the ability to function normally, rather than on long-standing traits within the individual. Duration of symptoms is not asked for, and thus the test will detect symptoms or dysfunction of very recent onset. This was considered an important factor, given the repeated measures design of the study. The research focus was the rate and quality of psychological recovery, and its relationship, if any, to the intensive care experience. It is conceivable that related problems could emerge at any time during the first twelve months, rather than showing a gradually decreasing incidence following initial physical recovery. In addition, patients might develop psychological symptoms *de novo*, in relation to some other stressor. Sensitivity to transient dysfunction was therefore considered a valuable feature of the GHQ.

The test's usefulness in longitudinal research has been demonstrated by Vachon et al. (1982) in an examination of factors predictive of adaptation to conjugal bereavement: the GHQ alone detected patterns of distress during grieving, with scores at initial one month follow-up the most powerful predictor of distress levels at two years. It has also been used to demonstrate increased stress perception from final year to pre-registration year, in a longitudinal study of junior doctors (Firth-Cozens 1987). It should be stressed that while scores above a certain threshold indicate the likelihood of a respondent being considered a "case" at clinical interview, the GHQ is a screening test only. The GHQ 28 sub-scales will demonstrate the extent of psychological symptoms, but are not in themselves diagnostic of psychiatric disorder (Goldberg & Williams 1991).

The GHQ assesses physical function and psychological status and has been used in many studies across a wide range of subjects and situations, as suggested by the authors' guide to the test (Goldberg & Williams 1988). It was considered a useful and suitable instrument for the purposes of this study. The author obtained a registration number from the publishers and was then able to purchase copies of the form and the manual.

Other generic measures were considered. The Sickness Impact Profile (Deyo et al. 1983) has been used in quality of life research after ICU (Hulsebos et al. 1991), and it is an accepted measure of sickness related dysfunction (Bowling 1991). However it is long, containing over one hundred items, and may take up to thirty minutes to complete. It was therefore rejected for use with these participants who, as noted earlier, were likely to be easily fatigued particularly at first follow up. The Nottingham Health Profile (Hunt & McEwan 1980) was also considered, this is a generic measure just slightly longer than the GHQ28. It was felt however that this might not adequately measure psychological distress in the way the anxiety and depression subscales of the GHQ28 can.

Despite the GHQ's range as a measure of quality of life or wellbeing, there were areas left unmeasured which were of interest. These unmeasured areas were the levels of self esteem in surviving patients, an aspect rarely measured separately in this group yet considered important in this context by the author, and also the presence of traumatic stress symptoms after discharge, an issue raised by recent research (Daffurn et al. 1994, Williams et al. 1994, Hall-Smith et al. 1997) that warrants further investigation. Two other screening tests were therefore added to the follow up assessment programme.

Although low self-esteem is a relatively stable component of depressive-prone personalities, in some individuals it may be a transient feature occurring as a result of various life events and experiences. Change in self-image and self-esteem may be of importance in ICU survivors, and a useful factor to consider in examination of psychological recovery. Abramson et al.(1978) identified the lowering of self esteem during illness recovery and linked it with the lack of control experienced by sick people. Self esteem has rarely been examined as a separate component of psychological recovery after ICU, and it was considered to be of importance in expanding the picture of psychological wellbeing.

The Rosenberg scale was developed from a study of self-esteem in adolescent subjects, but it has been widely used in research concerning self-esteem in older age groups (Wilson & Maguire 1985, Ingham 1986, Carpenter & Brockup 1994). In fact parallels can be drawn between the kind of worries occupying the adolescent's mind and those concerning the survivors of critical illness. Alteration in physical appearance may give rise to anxiety about body image in both the developing adolescent and the recovering patient; similarly in both groups uncertainty about or ambiguity of status may have a profound effect on self-esteem. While the adolescent experiences the pressures of searching for social roles and assuming adult responsibilities, the surviving ICU patient suffers the removal of these roles and responsibilities, at least temporarily, until recovery is complete.

Further, self-esteem or self-worth may be deeply affected by way of a traumatic experience *per se.* It has been suggested that highly stressful or traumatic events shatter ideas of self-worth as a result of the sense of extreme helplessness, uncontrollable reactions of fear and

diminished sense of competence surrounding the event. Assumptions about oneself are destroyed with consequent diminution of self-esteem (Janoff-Bulman 1985, Epstein 1990). Self-esteem loss may accompany the symptoms of post-traumatic stress disorder, symptoms which are also measured in this study by way of the Impact of Event scale, discussed later.

In a number of studies of patient recovery the Rosenberg scale has yielded useful data regarding psychological adjustment after illness. For example in evaluations of patients recovering from spinal cord injury (Overholser 1993) and of survivors of Hodgkin's disease (Cella & Tross 1986) associations have been found between self-esteem and anxiety or depression post-treatment. Research into psychosocial recovery after coronary artery bypass surgery, which routinely involves at least twenty-four hours of intensive care, has demonstrated a significant increase in self-esteem over the first six weeks across all age groups (Artinian et al. 1993)

The Rosenberg Self-esteem scale has the advantage of being short - completion takes a few minutes only - and easily administered. Subjects record their responses to seventeen statements. Positive and negative items are presented alternately to reduce the effect of respondent set (see Appendix VI). Scores are simple to calculate, with high totals indicating low self-esteem. The American Psychiatric Association was approached to ascertain the position regarding use of the form but no special application was required. The scale was thus a practical instrument to use in a survey conducted by post, the method of administration employed for the study, as well as being a source of relevant and useful information about this group of patients.

While the GHQ will measure the more general aspects of psychological functioning, and the Rosenberg scale assess self esteem, there was a further dimension to the experience of critical illness and ICU survival which must be assessed. The acute threat to life, and the radical high technology procedures involved in intensive therapy, may result in stress symptoms resembling

those seen in post-traumatic stress disorder (PTSD). The possibility of this syndrome arising in ICU survivors has been considered in Chapter Four.

The potential for PTSD has been identified by several studies (Williams et al. 1994, Hall-Smith et al. 1997, Schelling et al. 1998), but there is a relative paucity of research into the syndrome in ICU survivors, and its identification is important in a study of psychological recovery. Admission to, and survival within the ICU can be treated as a traumatic life event which may well put survivors at risk for stress response symptoms. Furthermore, the stress engendered by the experience may contribute to psychological dysfunction far beyond the point of physical recovery. Measurement of the symptoms of PTSD - intrusive thought and avoidance of stimuli - over an extended period of time was therefore an important element of this study in order to gain a comprehensive picture of psychological recovery.

The psychoanalytic perspective of Grubrich-Simitis (1987), who describes the structural damage done to the psyche, offers great scope for examination by case study but the author is not a psychoanalyst and this was not a feasible approach. A psychoanalytic approach would also raise the question of pre-trauma conflict and individual disposition in each patient. Wilson & Krauss (1985) have found the link between pre-morbid personality and PTSD development to be minimal, lending some support to the methodology for this study in which the influence of pre-morbid personality was certainly not ignored as a potential contributory factor to outcome, but was deemed hard to measure, post-admission, in any meaningful way, given the degree of sickness of the research subjects. As discussed in Chapter Four the concepts of shattering of constructs and the need to alter radically one's schemata (Janoff Bulman 1985, 1989, Horowitz 1974, 1976, 1979) seem particularly appropriate in relation to this research study, although a neurobiological approach might also be useful given the physiological disruption in ICU patients.

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The Impact of Event scale (IOES) has been developed and administered by Horowitz and colleagues for the assessment of long term stress, for example in patients receiving unforeseen and shocking diagnoses of life-threatening diseases, and in individuals who have experienced the sudden death of someone close to them. Symptoms of intrusive thought and avoidance of reminders have been demonstrated in subjects for up to three years following a stressful experience (Horowitz et al. 1980). This research, and other studies of the long term psychological consequences of traumatic events, has been discussed more fully in Chapter Four.

The IOES has been used in combination with the GHQ by a number of researchers examining the relationship between traumatic events and their psychological sequelae. McFarlane (1988) carried out an assessment of Australian fire-fighters following exposure to bushfire disaster. Symptoms of stress detected by the IOES, and of psychological impairment detected by the GHQ 12 item version, were found to be relatively discrete matters. That is, in an analysis of covariance of the two, results showed that distress (as measured by the IOES) accounted for only 14% of variance in psychiatric impairment (as measured by the GHQ). This implied that the relationship between distress and disorder is not necessarily linear, and other factors may operate to influence responses to disaster.

Others have used the GHQ and IOES alongside additional self-report measures in prospective studies of psychological disorder following such traumatic events as accidental injury, burns, cancer recurrence and minor head injury (Malt 1988, McFarlane 1988, Williams & Griffiths 1991, Cella 1990, Middleboe 1992). These studies demonstrate the benefits of combining a generic measure such as the GHQ with the more experience-specific IOES when conducting research of this nature - that is the ability to build a wider picture of distress in trauma survivors. McFarlane (1988), for example, measured distress after disaster in Australian fire-fighters, using a combination of the GHQ and the IOES. The study concluded that psychological dysfunction as measured by the GHQ, and distress caused by the event, as

measured by the IOES, were relatively independent. Williams & Griffiths (1991) used a combination of the Hospital Anxiety and Depression scale and the IOES to assess psychological consequences of burn injury. This combination allowed separation of anxiety, relatively common in these patients, from PTSD symptoms resulting from the burns accident.

For these reasons then, the IOES was considered a relevant and important instrument of assessment in the research undertaken for this thesis. As with the other tests employed, the IOES is brief - only fifteen items long - and easily understood. Permission to use the scale was obtained directly from its author after a fruitless search via the American Psychiatric Association. The scale was presented in its standard fifteen item format although an introductory explanation was added tailored to this patient group (see Appendix VII).

The combination of the Rosenberg Self-esteem scale, General Health Questionnaire and the Impact of Event scale was chosen in order to give a broad description of psychological recovery after critical illness and ICU admission. In this way one particular aspect of quality of life for these patients is considered. The aim of the study was to generate enough appropriate information, along with demographic and ICU data, to allow the identification of predictive outcome variables, should any exist.

Although the GHQ has been administered in conjunction with both the Rosenberg and the IOES scales separately, the use of the three tests together appears to be an innovation in this research domain. The literature reviewed indicates that research studies have identified important psychological problem areas for convalescing ICU patients, yet few if any have picked out the variables that might <u>predict</u> psychological outcome after discharge, allowing recognition of individuals with specific needs for intervention. There is also support for the use of longitudinal studies such as this; Smith & Avis (1999) have remarked on the need for long term assessment of survivors as treatments for life threatening diseases become more successful.

Long term outcome beyond ICU has been assessed both quantitatively and qualitatively, as seen in Chapter Two. Yet there remains a relative paucity of data, a conclusion also reached following a systematic review of the literature published in this area (Jones, Humphris & Griffiths 1998). This study aims to reduce this gap a little, and to enlarge, to some extent, the picture currently held of quality of life and psychological recovery after ICU, thereby adding to attempts to optimise emotional wellbeing for survivors. The suggestion made by Wilson & Cleary (1995) and outlined in Chapter Four, that investigation of the relationships between clinical variables and health related outcomes makes quality of life measurement more meaningful, lends support to the methodology used here. The results should identify a pattern of recovery for ICU survivors, and highlight those factors relating to risk of psychological damage. The defining of possible intervention methods is clearly an important adjunct to the prediction of problems, and this will be discussed in the concluding section.

As discussed in Chapter Four, Bowling (1991) has commented on the weakness of self rating scales in the measurement of improvement of quality of life - does the patient feel as though he or she is recovering, or not? This aspect of post ICU recovery is measured, if indirectly, within this study by way of the repeated assessments throughout the year. The choice of follow up or assessment points was made partly on a pragmatic basis. Longitudinal studies can be cumbersome and the study was to be carried out by a single researcher. It was anticipated - correctly - that sequencing of the follow up forms would become quite complex and the system was run not only using the computer database but with the aid of a magnetic wall planner. Six weeks, six and twelve months were relatively straightforward contact times, both for the researcher and the participants.

It was originally intended that the first assessment would be performed at one month, rather than six weeks. However it became apparent that there could be some overlap with the relatively new description of Acute Stress Disorder, which was included in the DSM-IV classification categories (F43.0, American Psychiatric Association 1994) and is distinguished from PTSD as symptoms occurring within two days of a traumatic event but also resolving within a four week period (Turnbull 1997). Newman & Lee (1997) agree that in acute stress disorder the pattern of symptoms and the existence of a traumatic event is similar, but should the pattern persist beyond four weeks then the diagnosis changes. Therefore the first follow-up point was set at six weeks in order to ensure that any presenting symptoms could be considered those of PTSD as opposed to the shorter lived acute stress disorder - though in fact the existence of this too would be of interest in an examination of psychological function after ICU.

### 6:2 The General Health Questionnaire

The General Health Questionnaire (GHQ) is a self-administered test which screens for nonpsychotic psychological disorders in adults and adolescents. It determines the respondent's ability to carry out normal functions, and also discloses any new or disturbing psychological symptoms. The GHQ was developed for use in non-psychiatric medical practice (Goldberg & Williams 1988). It has also been used to estimate the prevalence of minor psychiatric morbidity in the workplace and the community. Several versions exist: the GHQ 60, a full 60item test, the GHQ 30 and GHQ 12, shortened forms with items referring to physical illness removed, and a scaled version known as the GHQ 28.

### Development of the GHQ.

The test was devised at the Institute of Psychiatry in London as a screening instrument which would be:-

"specifically concerned with the hinterland between psychological sickness and psychological health"

(Goldberg & Williams 1988 p.5)

A range of questions or items concerning psychological functioning was composed, each relating to one of four major themes: depression, anxiety, social impairment or hypochondriasis. Items relating to personality traits, or to family or workplace relationships were excluded. Despite their potential for causing psychological upset, such items were considered not universally applicable and therefore not suitable for a broad screening test.

One hundred and forty selected items were presented to three calibration groups comprising "severely ill" and "mildly ill" patients from the Maudsley Hospital, and "normal" respondents selected by local door-to-door survey. Item analysis produced ninety-three questions which were significant discriminators between groups. Principal components analysis reduced these to a list of sixty, constituting the final GHQ 60 version of the questionnaire (Goldberg 1972).

A scaled version of the GHQ was developed by further factor analysis (Goldberg & Hillier 1979). A four-factor solution was obtained comprising clusters relating to somatic symptoms, anxiety and insomnia, social dysfunction and severe depression, and the seven highest loading items for each factor were taken to produce a sub-scaled test, the GHQ 28.

Respondents record experience of particular symptoms on a multiple-response scale from which scores are calculated (see Appendix V). Scaled sub-scores, and overall scores, can be used as a measure of the severity of psychological disorder. Several scoring methods are possible; the various alternatives, and the question of threshold scores, are discussed within the section on statistical analysis.

## 6:3 The Rosenberg Self-esteem Scale.

This test records a subject's assessment of his or her self-image by measuring self -esteem by way of perceptions of self-worth, self-respect and control over life. Self-esteem may be thought of as the evaluative component of a person's self-concept. If self-image is the picture we hold of ourselves, and ideal-self is the person we would like to be, self-esteem is an indication of how we evaluate the self-image. As Rogers (1961) has suggested, the wider the gap between self-image and ideal-self, the lower the self-esteem may be.

### Development of the Self-esteem scale

The Rosenberg self-esteem scale was devised as a result of research into self-attitude in late adolescence. Questionnaires were administered to a sample of five thousand students recruited from New York high schools, with respondents required to agree or disagree with items relating to various aspects of self-image and self-worth. Those subjects displaying positive self-image were described as better achievers, socially adept and relatively immune to criticism. The less confident adolescents - despite few differences in intellectual ability or physical attractiveness - tended to have a more negative image of themselves (Rosenberg 1965).

Defining self-esteem, and consequently attempting to measure it, are difficult tasks since it is determined entirely by individual psychosocial needs. The concept of validity in relation to self-esteem is difficult since no "known" or criterion group is readily available, thus validation of instruments is problematic. Detailed information regarding the scale's development is hard to find (Bowling 1991); Rosenberg's method was to compare the self-esteem scores of a group of fifty "normal" volunteers with their scores on a battery of characterisation tests. A statistically significant association was found between self-esteem scores, and data measuring anxiety, neurosis, symptoms of depression or discouragement, and lack of self-respect. The higher the score reflecting such features, the lower the subject's score on the scale, indicating a negative correlation between psychological dysfunction and self-esteem as measured by the Rosenberg scale.

The seventeen item test developed by Rosenberg as a result of his research has become a popular and widely used instrument. It can be sub-divided into subscales which measure negative self-esteem via sense of failure, uselessness, lack of self-worth, pride and self-respect, and positive self-esteem via high self-worth and satisfaction, ability, good qualities and positive attitude.

#### 6:4 The Impact of Event Scale.

In the course of clinical practice Horowitz (1974) noted the symptom of compulsive reminiscing frequently reported by individuals following stressful events. His studies, involving exposure of subjects to films of intensely violent or sad images, produced support for the hypothesis that intrusive and repetitive thoughts are a common human response to distressing experiences (Horowitz & Wilner 1976). Accordingly, Horowitz proposed that the presence of such thoughts could provide a specific measure of stress following a traumatic event.

Horowitz designed a self-rating scale containing items which would measure both intrusive thinking, and the avoidance of stimuli reminiscent of a distressing experience. Testing of the scale on subjects recovering from major life events such as bereavement, acute illness or severe injury, demonstrated its capacity to detect problems in a variety of circumstances. The scale focuses on the level of intrusive thought and avoidance rather than on the specific nature of the thoughts themselves, and thus may be applied to a diverse range of events. Categorisation into low, medium or high levels of symptoms is possible, allowing comparison of degrees of stress or distress within particular subject groups.

#### 6:5 Validity

Validity refers to the degree to which a test actually measures the attribute it is designed to assess - that is, how well the test achieves its intended aim. Validity is concerned with what a test measures,

and how successfully it does so, and as such must be established in specific relation to the particular trait or feature being examined. Though terminology for different types of validity varies, the three major categories generally described are content, criterion and construct-related validity.

#### Content validity:-

As the name implies this relates to the accuracy of the test content, that is to how well the test items - questions or statements - give an appreciation of the domain being assessed. One obvious form of content validity is "face validity" which is a superficial indication of the test's relevance or suitability - do the items look *prima facie* as if they will measure the intended area of behaviour? This of course depends on whose construct is meant - that of the professional working in the area, or that of the subject whose understanding and perceptions may be quite different. Nevertheless, face validity is of practical value since items which appear irrelevant or inappropriate may be met with suspicion both by test administrators and respondents, thus reducing the desirability of a test despite its objective validity (Anastasi 1990).

On a more technical level, content validation involves ensuring that test components cover as many aspects as possible of the behaviour or attribute being measured. This requires close prior examination of the behaviour domain in question and detailed description of the areas to be assessed or measured. Each test item should relate to one or more of the described content areas. By way of example, in the development of the Impact of Event scale, a measure of post-traumatic stress symptoms, the original test components evolved from a combination of clinical experience with clients undergoing psychoanalysis, open-ended interviews with individuals who had experienced stressful life events, and written reports of patients' experiences. This process allowed the description of a comprehensive list of items relating to stress after a life event, worded in such a way that they could be applied to any stressful event (Horowitz et al. 1979).

The proportion of items for each aspect of the attribute is also important since a test may become crowded with questions relating to more easily measured facets of a behaviour, yet be deficient in those which measure less tangible areas. For example in a measure of depression, questions or statements relating to sleep and rest - well understood by most people - may be easier to frame than questions about more nebulous concepts such as hopefulness or optimism for the future. Ideally the proportion of items for each area should reflect the relative importance of the attribute (Bowling 1991).

Content validity depends not only on the inclusion of appropriate items, but also on consideration of potential influences on subjects' responses. A test of numeracy, for example, may appear to be measuring mathematical ability but at the same time performance may be affected by candidates' levels of literacy. If the phrasing of items is complex, results may be biased in favour of more literate candidates and the test cannot be considered valid as a true measure of ability with numbers. Calculating an answer to a mathematics question framed in a detailed problem requires literary ability over and above the numeracy being tested.

Three principal steps are taken in order to ensure content validity. These are first, comprehensive examination of the area or attribute to be measured, secondly the drafting of clear "test specifications" to include definition of the attribute and the relative importance of each facet, and thirdly construction of items which fully meet these specifications. In the development of the General Health Questionnaire content validity was confirmed by the method of test construction. On the basis of the principal steps outlined above, a 140-item test was developed which was then calibrated by administration to three sets of patients, assigned to calibration groups according to degree of psychiatric disturbance - "severely ill", "mildly ill" and "normal". The original item analysis included results such as:-

Item	Group	C	Colui	nn	
		1	2	3	4
Have you recently felt.	•				
-restless and	normal	48	46	6	0
unable to relax?	mild	9	38	36	16
	severe	7	20	29	43
Have you recently had	<u>!</u> :-				
-restless and	normal	74	25	5 1	0
disturbed nights?	mild	37	33	3 2	22 8
	severe	16	20	5 2	26 31

from Goldberg & Williams 1991 User's Guide to the General Health Questionnaire, Appendix 1.

This calibration and analysis procedure was applied to the full list of items, allowing selection of those which discriminated between the calibration groups, thus ensuring a high degree of content validity (Goldberg 1972).

In the case of the Rosenberg Self Esteem scale, the Guttman technique was employed in the development of test items. This approach (Guttman 1944) seeks to overcome the problems of mixing the dimensions of the attribute being assessed, by the use of test items which have cumulative property and produce a unidimensional scale (Robson 1993). Statements pertaining to the focus of interest are administered to a standardisation group who record "agree" or

"disagree" responses. These responses are then analysed by scalogram. This technique involves a count of the numbers of agree/disagree responses per statement, or item. The items can then be arranged into a matrix where agree/disagree responses form a triangular pattern, as below:-

Respondent		1	2	3	4	5	6	7	8
Item	1	а	а	а	а	a	a	a	а
	2	d	a	a	а	а	a	а	а
	3	d	d	a	а	a	а	а	а
	4	d	d	ď	а	а	а	а	а
	5	d	d	d	d	а	а	a	a
	6	d	d	d	d	d	а	a	а
	7	d	d	d	d	d	d	a	а
	8	d	d	d	d	d	d	d	а

a = agree, d = disagree

(after Robson 1993).

This arrangement gives the items cumulative property: that is, the order in which they are presented means that acceptance of a particular item implies acceptance of a number of previous items. Once the best shape has been achieved the re-ordered test items are administered to a new group of respondents to establish the reproducibility of results (Robson 1993).

#### Criterion validity:-

This concerns the accuracy with which an attribute can be measured and involves correlation of the test with an independent measure of the area being examined - a "gold-standard" criterion.

Criterion-related validity provides evidence of a test's effectiveness in measuring and predicting performance in the area of interest. It is divided into two types, concurrent and predictive validity, which are differentiated by the time lapse between administration of the test and of the criterion measure.

To establish concurrent validity the criterion measure is taken at the same time as the test measure and both sets of results are subjected to correlation analysis. Criteria employed for validation depend upon the purpose of the test. In the case of intelligence tests some measure of academic performance such as current grades or teaching reports may be used; for psychometric tests of personality or mood then clinical diagnoses may be taken as the gold-standard reference.

In the case of the GHQ, comparison with independent psychiatric assessment was felt to be the most appropriate approach to establishing criterion validity (Goldberg & Williams 1991). A number of validity studies have been undertaken which have produced correlation coefficients ranging from 0.53 (Cairns et al. 1987) to 0.83 (Rabins & Brook 1981). A wide range of validity coefficients is available for the GHQ since it exists as several different versions and thus has been subjected to exhaustive validity studies. *Sensitivity* of the test - that is, the probability of a "true case" being correctly identified - and *specificity* - the probability of a "true normal" being correctly identified, can both be calculated as measures of validity. The GHQ28 has been administered to neurological in-patients producing a sensitivity of 80%, specificity of 81% (Bridges & Goldberg 1986). In a validity study performed on medical outpatients sensitivity and specificity emerged as 100% and 75% respectively (Selzer & Mann 1987).

The principal function of concurrent validation for any test is to establish its substitutability - can the test be used as a simpler or quicker alternative to the criterion measure? An example would be the development of a screening test for depressive symptoms to be used in place of time-consuming and expensive clinical interviews of subjects. If a strong correlation can be demonstrated between clinical findings and test scores, then the test could be considered to be a concurrently valid and

suitable replacement. Currently there is no gold standard for quality of life measurement in critical illness survivors - indeed it is difficult to think how such a varying area might be captured.

In contrast, the criterion reference may be a measure which is not immediately available but is obtained at a later date, thus indicating predictive rather than concurrent validity. The strength of the relationship may be taken as an indication of the predictive validity of the original test - for example infants may take an intelligence test at two and five years and the two sets of results correlated (Ireton et al. 1970, McCall et al. 1972).

Predictive validity can also inform users if a test has ability to measure future differences - that is, if it can be relied upon to forecast a subjects' performance or behaviour at some point in the future. For example the Rosenberg scale has demonstrated predictive validity in relation to depression symptoms (Bowling 1991). Predictive validity is of particular significance in tests developed for the purpose of screening or selection - for example in occupational psychology.

#### Construct validity

This is of especial relevance to psychological and sociological testing, relatively abstract or indeterminate areas where the variables to be tested are not directly measurable. Here the areas of interest may have been described theoretically but ultimately the test has been developed to measure a purely hypothetical construct. A number of different methods may be employed to establish construct validity.

<u>Convergent-Discriminant Validity</u>: pre-existing tests which claim to measure the same construct may be used in the validation of a new test. If a moderate degree of correlation can be demonstrated then both can be assumed to be dealing with a similar construct. Should the correlation be high - a coefficient approaching 0.8 or 0.9 - then in the absence of some significant innovation the question of unnecessary duplication arises. Similarly, if a new test correlates highly with measures of different, though related constructs, this may be evidence that inappropriate or irrelevant factors have been included. For example a test of mood or affect should not correlate too highly with personality tests, as this might make the test questionable as a measure of affect alone. However a low correlation does not in itself confer validity (Anastasi 1990). These two processes are known respectively as <u>convergent</u> and <u>discriminant</u> validation. Convergent validity of the Rosenberg scale with the Coopersmith Self Esteem inventory (Coopersmith 1967), has been examined by Robinson & Shaver (1973) who reported a correlation coefficient of 0.6, indicating that both tests deal with the same construct.

It is possible to examine convergent-discriminant validity with one procedure using the multi-trait multi-method matrix described by Campbell & Fiske (1959), cited in Anastasi 1990. This involves measuring two traits using two different methods and producing a correlation matrix for the results obtained. For construct validity to be established the correlation between same-trait scores obtained by different methods must be higher than the correlation between different-trait scores obtained by the same method.

<u>Factor analysis</u>: this statistical technique simplifies large numbers of variables by identifying underlying dimensions; in this way a large number of test items can be reduced to a smaller number of components, thus refining the test. The technique is of relevance to construct validation in that all the original items can be subjected to a factor analysis. If the items are measuring certain common traits then a number of dimensions or factors will be identified. This simplifies the test, and allows a clearer description of the construct it is measuring. Factor analysis also enables the formation of sub-scales which may lend more meaning to scores, particularly for research purposes. The construction of the GHQ used the technique of principal components analysis, where the combination of variables which accounts for the most variance in the data is calculated. The four main areas defined were depression, anxiety, social performance and somatic complaints (Goldberg & Williams 1991).

Similarly cluster analysis may search out groups of items. Horowitz et al (1979) subjected the Impact of Event scale to cluster analysis which yielded distinct subsets of items which might indicate stress following life events. For example one cluster included items such as:-

I thought about it when I didn't mean to Images related to it popped into my mind I had bad dreams related to the event

while another cluster included such items as:-

I avoided letting myself get emotional when I thought about it or was reminded of it I wished to banish it from my store of memories I stayed away from things or situations that might remind me of it

Horowitz, Wilner & Alvarez 1979

From the initial four clusters it was possible to develop two subscales - intrusion and avoidance - within the scale.

#### 6:6 Reliability

If a test is to be considered trustworthy or reliable it must be capable of consistently producing the same results, especially over time but also under differing conditions. Reliability estimates are calculated on the strength of the relationship between independently obtained sets of scores, thus, as with test validation, a correlation coefficient is produced. One of the reliability coefficients most commonly used is Cronbach's alpha (Cronbach 1951) which is based on the internal consistency of the test - that is the average correlation of the test items with each other. Cronbach's alpha - used to check reliability within this study - calculates an average of all the split half coefficients in the

given test. As with other correlation coefficients Cronbach's alpha can range in value from -1 to +1, though negative values, rather than indicating some interdependent relationship between items, imply that there is no correlation among test items and reliability is therefore absent. The alpha coefficient should be > 0.85 for acceptable internal consistency (Norusis 1990). The reliability test indicates what proportion of individual differences between scores is due to chance, and what is due to true fluctuation in the behaviour or characteristic being measured - that is, what the proportion of error variance is.

Three methods of measurement are generally used to estimate this error variance: split-half, multiple or alternate form, and test-retest reliability.

<u>Split-half reliability</u>: with this method the two sets of scores to be correlated may be obtained from a single administration of the test, by dividing it into equivalent parts and correlating the resulting scores. Thought must be given to the way in which the test is divided to ensure parity of the two halves and guard against a false estimation of the reliability. In many tests items at the beginning will be markedly different to those at the end, precluding a straightforward split into first and second halves. Further, division of the test can be problematic unless the items have some degree of homogeneity with regard to the behaviour or attribute being measured - too much variation may result in the creation of test halves which are measuring quite distinct aspects of the attribute in question, thus the reliability coefficient may be spuriously lowered. The problem of comparable halves was met within the GHQ by pairing items on the basis of content and of the responses found at item analysis, then randomly assigning the first question in each pair to the first or second half, the second to the opposite half. This procedure resulted in split halves which were equivalent both in conceptual content - that is, the feature they were measuring - and discriminatory power, as demonstrated by the response gradient in the item analysis (Goldberg & Williams 1991).

<u>Alternate-form reliability</u>:-this method allows a combination of the above two types of reliability. It involves administering alternate forms of the same test on two occasions, and correlating the scores on each. The two forms need to be developed in parallel - constructed to the same test specifications, containing the same number of items and having equivalent content in respect of the attribute being measured.

Test-retest reliability: here the test is administered to the same subjects on two separate occasions and the two sets of results correlated. The error variance will correspond to chance fluctuation in performance over the two occasions, due either to some variation in the condition of the subjects themselves or to a change in testing conditions. Test-retest allows an estimation of the generalisability of the test - how applicable will the findings be at other times or in another context? (Robson 1993). The interval between testing will have a bearing on the retest correlation, as might the experiences and changing circumstances of the subjects. On its own, the first administration of the test may affect a participant's response at the second. Factors such as these can complicate the interpretation of reliability, therefore the length of interval, intervening experience and the possibility of practice effect should all be taken into account when considering test-retest reliability. These considerations are particularly pertinent to some psychological tests, where the quality being measured may be highly variable and scores very susceptible to changing experience. Self esteem, for instance, tends to fluctuate across time and events - indeed it is this property which makes it a useful variable in studies of wellbeing - although it is interesting to note that a high test-retest correlation was reported by Rosenberg in the case of the Self Esteem scale (Rosenberg 1965).

Because of the potential problems of variability it has been suggested that this method of establishing reliability is perhaps best suited to tests which are less likely to be influenced by repetition - for example motor or sensory discrimination tests (Anastasi 1990). However the method may still be attempted in reliability studies of psychological tests, and is further illustrated by the selection of patients for test-retest studies of the GHQ, where a population sample was required whose clinical status did not alter over a period of months. This requirement was met by subjects attending general practitioners' surgeries in whom a stable degree of disturbance was assessed by standardised psychiatric assessment. Although test-retest correlations were found to be

high for this clinically defined group, the authors admit that this method of establishing reliability has not yet been fully explored for the GHQ (Goldberg & Williams 1991).

### **CHAPTER SEVEN. METHODOLOGY**

#### 7:1 Research setting

From 1st May 1994 to 1st March 1996, a cohort of surviving patients was established from within the Intensive Care Unit at St James's University Hospital in Leeds, West Yorkshire. The unit serves 1100 beds within the hospital; during the course of the study the ICU was relocated within a new wing at which time it was expanded from nine to eleven beds.

Patients are admitted to this ICU from a wide range of specialities including general, vascular and orthopaedic surgery, hepatic failure and transplantation, acute renal failure with continuous filtration, major reconstruction plastic and microvascular surgery, trauma (excluding severe head injury), adult and paediatric oncology and haematology, obstetric and gynaecological emergency, and respiratory failure requiring advanced technology and medical support. The hospital is a regional centre for renal and hepatic transplantation and the unit routinely admits patients following liver transplant for initial post-operative care.

The nursing establishment for the unit is based on 108 full time staff, at an estimated cost of  $\pounds 2,500,000$  per annum. The medical staff includes four consultant intensivists one of whom is Unit Director, and a rotation of junior anaesthetists. In addition the unit is supported by secretarial staff, a ward assistant and a data information officer (data confirmed by Senior Nurse April 1999).

#### 7:2 Sample and recruiting strategy

Devising a sampling frame for the study presented certain problems; it was known that a high proportion of the patients admitted to the ICU would be ineligible for a follow-up study of psychological wellbeing. With an average in-unit mortality rate of 28% a substantial

proportion did not survive to discharge. Mortality rate while still in hospital - that is after discharge from ICU but before discharge home - is calculated at 12%, while a further 6% of survivors may be expected to die within six months of the original admission (1993-4 unit data). Further, the rigorous selection criteria meant that the number of recruitable subjects was likely to be relatively small, making true random sampling a problem.

The research sample was chosen on a strategic basis; strategic or purposive sampling involves the establishment of criteria for inclusion, then selection according to these criteria. By using clinical experience to make conscious selection decisions, confounding variables can be reduced to a minimum. Here subjects were required who could potentially supply useful and relevant information regarding emotional or psychological recovery following the ICU experience. This strategy undoubtedly introduces a degree of selection bias in that decisions are based on experience and notions of one particular researcher or group of researchers. As such it compromises generalisability of findings somewhat. However the experience used was not just that of the author, who has worked for a number of years in several different ICUs, but also that of nursing and medical colleagues with considerable combined clinical experience, and the strategy employed certainly sought to ensure optimum internal validity.

Patients initially considered for the study had to meet the following broad entry criteria: age over eighteen years (in accordance with recommendations for the psychometric assessments used) and admission to the ICU for forty-eight hours or longer. Of the 1573 patients admitted to the ICU during the recruitment period, 599 met the broad criteria and were screened for admission to the research project (see Figure 7:i Development of the Research Sample). It will be seen that the number of patients available for the entire research period was inevitably a small percentage (38%) of the total patients passing through the ICU. Recruitment difficulties, then, had a large effect on the time scale of the study, since clearly too few subjects mean difference may simply reflect natural variability.

The major exclusion criteria were any history of mental illness, and the sustaining of cerebral damage prior to or during admission. These were considered to be confounding factors to outcome prediction by this particular study since the variables to be measured related to psychological wellbeing in the recovery period. A susceptibility to or a previous experience of mental illness may have coloured responses such that association with the ICU experience may be hard to discern. Perhaps more obviously, cerebral damage would make assessment difficult both in terms of actual participation and of comparison of results with undamaged participants. A number of other factors led to the exclusion of patients: these included concurrent bereavement, no English, and lack of consultant consent. In all 408 of the patients screened on ICU were deemed ineligible for inclusion for a variety of reasons, or excluded themselves.

After exclusion of 408 patients, 191 were approached regarding possible participation. These were visited on the ward within a few days of discharge from ICU. The researcher introduced herself and told each patient about the purpose of the research. A combined information sheet and consent form was left with the patient (see Appendix II) and a further visit arranged. At this second interview patients were invited to ask questions about the study, and those willing to participate were asked to sign the consent clause. 119 potential subjects were lost at this stage, primarily due to deterioration or death on the ward. This number included 28 patients who were discharged before the second ward visit and 8 who declined to join the study. All consenting participants - a total of 72 patients - were given their own copy of the information sheet and consent form, with contact numbers for the researcher in the event of any queries or problems.

# Figure 7:i : Development of the research sample.

Potential numbers		Excluded at each st	age
Total admitted in			
recruitment period	1573		
		Failed criteria	974
Total > 18 years and			
>48 hours stay	599		
(all screened)			
		Psychiatric history	33
		Died on ICU	238
		No consultant consent	62
		Transfer to other hospital	32
		No English	15
		Other	28
Approached on ward	191		
		Discharged early	28
		Deteriorating rapidly	62
		Died on ward	21
		Refused consent	8
Consented	72		
		Non-responders	9
		Died before 1st follow-up	7
		Requested withdrawal	2
		Readmitted, complications	2
		Withdrawn by researcher	7
		Returned to own country	1
		Died during follow-up	7
Full 12 months attained	<b>7</b> 7		

### 7:3 Patient and ethics consent:-

Informed consent was obtained from all patients, from the staff of the ICU, and the research project was approved by the Ethics Committee at St James's University Hospital (see Appendix I). Consent was also sought from individual consultants in the hospital for agreement to approach patients under their care. This was done both out of courtesy and to fulfil the requirements of the hospital Ethics Committee. The majority of consultants agreed and expressed support and interest; disappointingly a few failed to respond despite repeated request, and thus quite a number of potential subjects were lost to the study.

### 7:4 Procedure

Data were collected from three sources - patient records, patient comments at interview, and subsequently self-report questionnaires. Once consent had been obtained each participant's medical and nursing notes were examined to abstract information about the time spent on the ICU. The data sheet devised for this purpose is reproduced in Appendix III.

Information recorded included the following:-

### **Demographic characteristics -**

- Age
- Sex
- Marital status
- Occupation.

### Clinical data -

- Mode of admission categorised as:-
- 1. Elective
- 2. Conscious from the ward
- 3. Unconscious from the ward
- 4. Conscious from Accident & Emergency
- 5. Unconscious from Accident & Emergency
- 6. Unplanned from operating theatre
- Indication for admission categorised as:-
- 1. Respiratory disease
- 2. Cardiovascular disease
- 3. Trauma
- 4. Metabolic/endocrine disease
- 5. Transplant surgery
- 6. Planned surgery
- 7. Unplanned surgery
- Admission severity score (Day 1 APACHE score).
- Length of stay in ICU (in days)
- Length of stay in hospital (in days)
- Sedative and analgesic drugs administered.
- Muscle relaxant drugs administered these are neuromuscular blocking agents which induce a temporary generalised paralysis, necessitating full respiratory support from the ventilator. Short term relaxants are administered to all patients at intubation, but longer

term relaxants may be given to some patients over an extended period to improve ventilation and oxygenation in difficult cases, although the use of these drugs as an adjunct to ventilation has diminished greatly with the availability of highly tailored ventilatory techniques in modern ICUs.

• Whether cancer was part of the original problem.

### Social factors -

- Whether or not relatives were resident on the ICU during the admission period.
- Social support anticipated on return home.

The social support data were based on structural rather than functional features, simply as a measure of the closeness of social contact. A record was made of whether:-

- 1. Patient lives with next of kin.
- 2. Patient lives alone, with next of kin nearby.
- 3. Patient lives alone with friends/neighbours nearby.
- 4. Patient lives alone with minimal support available.
- In the case of trauma victims, the involvement and injury or death of others was recorded.

### Recall -

• Participants were asked about their memories of the ICU and about their ability to communicate with staff and relatives while ventilated.

Data regarding recall were obtained by asking how clearly, if at all, patients were able to remember certain features of treatment. These were based on method of data collection used by Bergbom-Engberg et al. (1988) in their study of patient recall, described in Chapter Two.

The patient was asked:-

"Can you remember the following things (1) not at all (2) vaguely (3) quite clearly"

"Having an endotracheal (breathing) tube in your throat?"

"Breathing via the ventilator (breathing machine)?"

"The vascular lines (drips) which were attached to you?"

"Where your bed was in the intensive care unit?"

"The presence of nursing/medical staff/relatives?"

### Sleep -

- Patients were asked to assess the quality of the sleep obtained on the ICU by saying whether he/she:-
- 1. Feels he/she slept well.
- 2. Feels he/she got a reasonable amount of sleep.
- 3. Feels he/she slept poorly.

# **Communication** -

• Data regarding communication were obtained by asking <u>one</u> question, based on the method of data collection by Ashworth (1980) in her study of communication in ICUs.

The patient was asked:-

"When you tried, were you able to make most people understand what you wanted?"

Responses to this were coded for Yes or No.

Participants were contacted by telephone after discharge from hospital, both to establish their continued survival and ensure their ability and continued willingness to participate. At six weeks post-discharge from the ICU copies of the GHQ, the Rosenberg Self-esteem scale and the Impact of Event scale were then sent to each participant along with a covering letter (Appendix IV) and a paid reply envelope addressed to the Intensive Care Unit at the hospital. (A few patients were still in the hospital at the six week follow up point, these were visited on their ward). The questionnaires were identified by a number - for example 20/1, signifying Case number twenty, first set of forms; participants were also reminded in the letter that they need not write any name on the forms, thereby reiterating the original assurance that only the author would be able to identify respondents from returned forms.

This pattern was repeated at six and twelve months following discharge. With the final set of questionnaires each patient was also asked about any other potentially stressful life events experienced during the year since discharge from the ICU (see Appendix VIII). Reminders were sent to non-responders, who were not considered lost to the study until the end of the twelve month post-discharge period. All subjects who had originally consented to participate, and who had not expressed any wish to withdraw, continued to receive mailings at designated follow-up times in the hope that they would respond to the research.

### 7:5 Statistical analysis:-

Data were analysed using the Statistical Package for the Social Sciences (SPSS/Windows). Copies of the tests can be found in Appendices IV, V and VI. Scoring was carried out in the following way:-

**GHQ28** - In this study the subscale scores were potentially of interest, therefore simple Likert scoring was used, as advised by the authors' guide (Goldberg & Williams 1991). Likert scoring provides a composite measure, allowing location (within the bounds of the particular test) and measurement of the intensity of any problems as perceived by the respondent. The responses were rated 0 - 1 - 2 - 3 across columns, allowing perceived intensity of dysfunction, if present, to be ascertained. Increase in GHQ scores indicates increase in psychological dysfunction.

Self esteem, Impact of Event scales - These too were scored by a simple Likert method as suggested by the authors (Rosenberg 1972, Horowitz & Wilner 1978). Increase in scores on the Rosenberg scale indicates <u>lowering</u> of self esteem; increase in scores on the Impact of Event Scale indicates increase in symptoms of post traumatic stress.

Thus in the case of all three tests, higher scores indicate worse psychological function. Maximum possible scores are shown in Table 7a below.

Test	No. of items	Minimum	Maximum
GHQ28	28	0	84
SES	17	0	51
IOES	15	0	45

### Table 7a: Potential range of scores for each test

The data were analysed in several steps. First, an initial analysis was undertaken which produced descriptive statistics, and determined whether there were statistically significant differences between different subgroups for the dependent variables - that is outcome scores on the three assessments at the separate follow up points. This identified variables which might profitably be included in the subsequent analysis. Reliability analyses were undertaken on the three tests, and tests for normality performed.

The second step of the analysis involved entering the significant subgroups into a correlation analysis with the assessment scores, to confirm any statistically significant relationships with the outcome scores.

Thirdly, those variables which emerged as statistically significant were entered into a regression analysis to determine which might have some predictive ability in relation to outcome scores. These three steps achieved objectives two, three and four of the study (as outlined in Chapter One) and generated the means to develop possible patterns of psychological recovery from discharge to the end of the first year of survival.

### **CHAPTER EIGHT. DESCRIPTIVE AND SUBGROUP ANALYSIS**

### 8:1: Descriptive statistics

72 patients formed the original sample for the study, 50 males (69.4%) and 22 females (30.6%).

Mean age was 49 years, mean length of stay in ICU 6 days, and mean length of stay in hospital overall was 32 days. Descriptive statistics for these variables are presented in Table 8a.

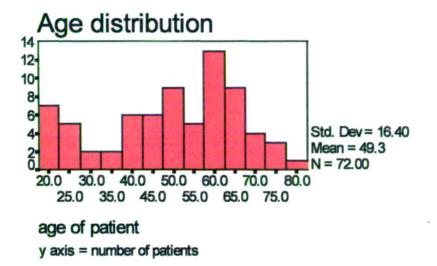
### Table 8a. Descriptive statistics for sample

Variable	Mean	S.D	Minimum	Maximum	N.
Age(yrs)	49.3	16.4	19	78	72
Days ICU	6.2	4.6	2	23	72
Days SJUH	32.5	20.1	7	120	72

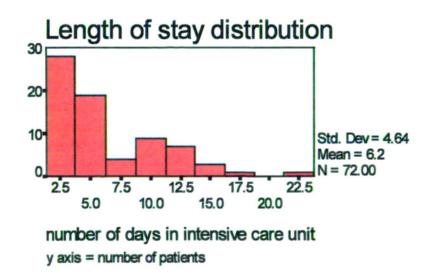
Days ICU = Number of days as a patient in the Intensive Care Unit Days SJUH = Number of days as a patient in the hospital

Distribution patterns of these variables are displayed below, indicating a negative skew for patient age, in line with admissions to ICU generally, and a positive skew for lengths of stay in both ICU and hospital, indicating that most patients spent less than the mean times stated above.

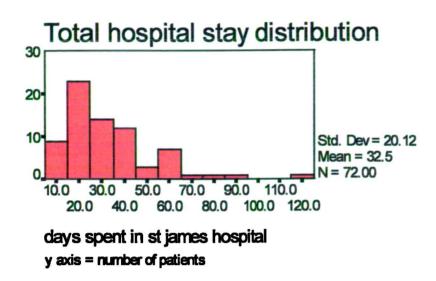
# Figure 8:i Age distribution of sample.



# Figure 8:ii Length of stay distribution of sample



# Figure 8:iii. Hospital stay distribution of sample.



Patients' ages cross tabulated with indication for admission demonstrates the different nature of illnesses across the age span.

	Respir-	Cardio-	Trauma	Metab-	Transp-	Planned	<u>Unplan-</u>	TOTAL
	atory	<u>vascular</u>		<u>olic/en-</u>	<u>lant</u>	surgery	ned	
				docrine			surgery	
<u>18-30yr</u>	4		4		3	2	1	14
<u>31-43yr</u>	2		2	1	3	3	1	12
<u>44-56yr</u>	8	2	1	5	9	6	4	35
<u>57-69yr</u>					2	4	4	10
<u>70-82yr</u>	1							1
TOTAL	15	2	7	6	17	15	10	

### Table 8b: Crosstabulation, age groups and indication for admission.

### 8:2 Sample attrition

Intensive care survivors are a high mortality group and despite a good response rate to the postal follow up a degree of attrition inevitably occurred, primarily within the time between recruitment and first follow up.

• 14 patients (19%) altogether died before the end of the twelve month follow up period.

7 died between recruitment and 6 week assessment3 died between 6 week and 6 month assessment4 died between 6 month and 12 month assessment

- 11 (15%) were withdrawn from the study before follow up was commenced:-
  - 2 withdrew at own request once discharged home.
  - 4 required transfer to long term care
  - 2 were readmitted with serious complications
  - 3 emerged as having undisclosed psychiatric problems
- 9 (12.5%) failed to respond to follow up.
- 1 (1.4%) returned to her native country and was unfortunately lost to the study.

Thus the sample emerged as:-

- 44 subjects followed up to 6 week assessment (61% of original sample)
- 41 subjects followed up to 6 month assessment
- (57% of original sample)

(51% of original sample)

• 37 subjects followed up to 12 month assessment

This resulted in missing data in the second and third follow up groups.

It was possible to employ one of the missing data strategies provided by SPSS, when undertaking the subgroup analyses, and the further correlation and regression. These strategies are first, the "listwise" technique where cases with missing values for any variable are excluded from all analyses, and second, the "pairwise" or "casewise" technique where cases with missing values for particular variables are excluded from analyses involving those variables (Norusis 1993).

From first follow up at 6 weeks, to final follow up at 12 months, 7 patients were lost. As seen previously the bulk of the sample attrition occurred before follow up could commence. On examination, minimal difference in the subgroup analysis was detected between pairwise and listwise missing value treatment (see Appendices XI and XII). The general score patterns across the twelve months were calculated with missing values treated "listwise" - that is any case which does not have data for all variables is excluded from the analysis. It was felt that this gave a truer picture of overall scoring patterns.

The subgroup and regression analyses were carried out on the sample as it diminished from 44 to 41 to 37, and the figure for sample size (n) is quoted in tables and charts throughout.

Within the results section for the subgroup analysis the frequency distribution for each variable shows how and where the sample attrition occurs. The patients who died during the follow up period comprised in fact a quite random group, in that examination of the variables showed no strong indication that any particular subgroup had more deaths (see Appendix X for characteristics).

As a precaution, the subgrouping tables were also run on the sample with missing values excluded "listwise" - that is where any case with missing data for any variable is excluded.

This meant that the analysis was run only on the 37 cases who survived to the final 12 month follow up. The values obtained for the outcome scores using this method are presented in Appendix XII and it will be seen that any differences to those obtained using the "pairwise" treatment are small.

#### 8:3 General pattern of scores

Reliability of all tests has been confirmed as discussed previously; as an extra check Cronbach's Alpha was calculated yielding the following coefficients:-

### Table 8c. Reliability coefficients

TEST	6 weeks	6 months	12 months
GHQ28 - 28 items	.9146	.9587	.9604
SES - 17 items	.9111	.9101	.9096
IOES - 15 items	.8980	.9151	.9532
	n = 44	n = 41	n = 37

(All values of alpha > 0.85 implying acceptable internal consistency as discussed in Chapter 6.)

In addition as part of the subgroup analysis tests for normality were performed on the outcome measures. The Shapiro Wilks test for normality was chosen given the small size of the sample, particularly by the end of the follow up period (see sample attrition). Test statistics and significance levels are as shown in the table below:-

Table 8d. Shapiro	Wilks test statistics	for psychometric assessments

S-W	ghq6w	ghq6m	ghq12	ses6w	ses6m	ses12	ioes6w	ioes6m	ioes12
Stat.	.86	.84	.88	.96	.95	.96	.93	.91	.84
Sig.	<.01	<.01	<.01	.48	.23	.35	.04	<.01	<.01

ghq6w = GHQ28 scores at 6 weeks ghq6m = GHQ28 scores at 6 months ghq12 = GHQ28 scores at 12 months

ses6w = Self esteem scores at 6 weeks

ses6m = Self esteem scores at 6 months

ses12 = Self esteem scores at 12 months

ioes6w = Impact of Event scores at 6 weeks

ioes6m = Impact of Event scores at 6 months

ioes12 = Impact of Event scores at 12 months

This was done in order to examine the assumptions underlying the analysis, though the caveats relating to quantitative methods applied to social scientific data are acknowledged earlier in the thesis, and non-parametric tests have been used throughout the subgroup analysis. It can be seen that the Self esteem scale results cannot be said to come from a normal distribution, while those from the GHQ28 and the IOES did in fact fit this test for normality despite the small sample size.

A general pattern of results was established by the initial analysis which gave an overall picture of recovery within the research sample. As discussed previously, simple Likert scoring (0-1-2-3) meant that the maximum possible scores on each test were as shown in Table 7a, with a possible GHQ maximum of 84, SES maximum of 51, and IOES maximum of 45.

Initial descriptive statistics from the study are presented below:-

	Mean	Median	SD	SE	Max	Min	95%CI
ghq6wks	23.1	22	13.1	2.2	65	6	18.7,27.5
ghq6mos	21.2	17	14.9	2.5	65	3	16.2,26.2
ghq12ms	21.5	18	14.6	2.4	58	3	16.6,26.3
ses6wks	16.5	17	8.3	1.4	32	0	13.7,19.2
ses6mos	15.3	17	7.9	1.3	29	0	12.7,17.9
ses12ms	16.6	15	8.3	1.4	32	0	13.8,19.4
ioes6wks	13.7	12	9.8	1.6	33	0	10.4,16.9
ioes6mos	12.4	12	10.3	1.7	33	0	8.9,15.8
ioes12ms	11.5	8	12.2	2	41	0	7.5,15.6

#### Table 8e. Descriptive statistics for all assessment scores.

CI = Confidence intervals

As indicated by the figures above psychological function, reflected by mean GHQ28 scores, improved slightly between first and second follow-up, with a drop in mean score from 23.1 at 6 weeks, to 21.2 at 6 months. At final follow-up the mean score had risen slightly, back to 21.5.

Self-esteem mean scores also indicated improvement from first to second follow-up, keeping pace with GHQ28 scores. Mean self esteem score at 6 weeks was 16.5, falling to 15.3 at 6 months. By final follow-up however the mean self-esteem score had risen to its original level (16.6) indicating a slight perceived drop in self-esteem at 12 months post-discharge, in parallel with the perceived drop in wellbeing as measured by the GHQ28.

The overall pattern of post traumatic stress symptoms, as indicated by mean IOES scores, suggested a gradual reduction of both avoidant and intrusive thought over the follow-up period. The initial mean score measured at 6 weeks was 13.7, this fell to 12.4 at 6 months and to 11.5 at 12 months.

A Wilcoxon test for related samples was performed on the mean total scores for the GHQ, SES and IOES at 6 week, 6 months and 12 months follow-up points, in order to discern any statistically significant changes occurring to these scores over time. Mean scores did not differ significantly between the follow-up points, an indication that there was not a significant change in scores, in either direction, over the follow-up period. Significance levels are shown below:-

# <u>Table 8f: Wilcoxon tests on total scores for General Health Questionnaire, Self-esteem</u> <u>scale, Impact of Event scale: p-values</u>

Paired groups	Significance level
Total GHQ 6 months - Total GHQ 6 weeks	p<0.15
Total GHQ12 months - Total GHQ 6 months	p<0.87
Total GHQ12 months - Total GHQ 6 weeks	p<0.34
SES 6 months - SES 6 weeks	p<0.15
SES12 months - SES 6 months	p<0.11
SES12months - SES 6 weeks	p<0.63
IOES 6 months - IOES 6 weeks	p<0.10
IOES12 months - IOES 6 months	p<0.67
IOES12 months - IOES 6 weeks	p<0.20

Appendix IX displays the patterns of scores across the follow up period.

### 8:4 Incidence of dysfunction in participating patients.

The percentage of patients presenting with psychological dysfunction was also of interest. The following three figures display the proportion of patients whose scores suggested some degree of dysfunction.

NB: These calculations have taken into account the sample attrition between each follow-up point.

# The GHQ28

In the case of the GHQ28, use was made of threshold scores. The threshold score indicates the number of recorded psychological symptoms at which the probability of being diagnosed as a "case for treatment" is > 0.5. That is, that at an independent clinical interview a diagnosis of psychiatric caseness would be made by a clinician (Goldberg & Williams 1991).

It is suggested that distinction between "caseness" and "non-caseness" is not relevant where psychological dysfunction is being used as a dimension in research - the situation here. Nevertheless threshold score can give a useful reference point where there is interest in the proportion of patients, in a particular sample, which displays psychological dysfunction. The best suggested threshold score when using simple Likert scoring as in this study, is 39/40 (Goldberg & Williams 1991, p19).

# Table 8g: Percentage of patients displaying dysfunction on GHQ28 scores.

	Surviving patients	No. scoring > 39*	Percentage of surviving sample
Six weeks	44	6	14%
Six months	41	6	15%
Twelve mont	hs 37	6	16%

(Possible scores - Max 84, Min 0)

### \* best threshold

### The Self Esteem scale.

When scoring the Rosenberg self-esteem scale using a simple Likert method, high scores reflect low self esteem. The maximum possible score is 51. Here the proportion of patients which scored 25 or more on the Self esteem scale, is displayed in Table 8g. These patients may

be considered as recording self esteem which is relatively low.

### Table 8h: Percentage of patients with Self Esteem scores greater than 25

(Possible scores - Max 51, Min 0. High scores reflect low self esteem).

	Surviving patients	No. scoring >25	Percentage of surviving sample	
Six weeks	44	9	20%	
Six months	41	5	12%	
Twelve month	is 37	9	24%	

### The Impact of Event scale.

Horowitz et al. (1981) have suggested threshold scores for the Impact of Event scale to distinguish between levels of post traumatic stress. High scores (>19) indicate that symptoms merit concern, may indicate pathology, and evaluative or treatment procedures are warranted. Medium scores (>9, <19) suggest that symptoms may give a global indication of a condition warranting further evaluation. Low scores (<9) suggest no cause for concern over symptoms, and no indication for any further evaluative or treatment procedures (Horowitz et al. 1981)

#### Table 8i: Percentage of patients displaying medium/high Impact Of Event Scale scores

	Surviving	Medium	% surviving	High	% surviving	
<u> </u>	patients	>9 <19	sample		> 19	sample
Six weeks	44	12	27%	17	39%	
Six months	41	8	20%	13	32%	
Twelve mths.	37	10	27%	10	27%	

(Possible scores - Max 45, Min 0)

### 8:5 Subgroup analysis

Analysis of scores obtained at the three data collection points revealed a number of discernible differences among subgroups with regard to several demographic and ICU variables.

For simplicity the subgroup analysis is reported by level of measurement:-

# Interval/ratio variables

- Age
- Length of stay in ICU
- Length of stay in SJUH
- Admission severity score

### **Ordinal variables**

- Recall
- Communication
- Social support
- Sleep

# **Categorical variables**

- Occupational classification
- Mode of admission
- Illness/indication for admission
- Sex
- Presence of relatives
- Muscle relaxant therapy
- Cancer diagnosis
- Coincidental life events

The individual values of the outcome scores - mean, median and standard deviations - for all subgroups are presented in tables in Appendix XI.

Test statistics and significance levels for all subgroups are presented in tables in Appendix XIII.

## Age

To simplify interpretation of these data, patients' ages were classified into five groups and mean total scores submitted to analysis. In constructing classification groups or categories, too few or too many may distort the distribution. It has been proposed that the number of categories should be between five and twenty (Bowers 1996). Bryman & Cramer (1994) describe six to twenty categories as commonly approved, but add the proviso that with relatively few cases, fewer than six categories are permissible to allow a workable number of cases per category. Here age was grouped in five categories.

The frequency grouping was as follows:-

## Table 8j: Grouped frequency distribution, Age.

		COUNT					
Category	Description	Original	6 weeks	6 months	1 yr.		
1	18-30yrs	14	8	7	6		
2	31-43yrs	12	7	7	7		
3	44-56yrs	35	24	22	20		
4	57-69yrs	10	5	5	4		
5	70-82yrs	1	0	0	0		
Total	· ·	72	44	41	37		

From analysis of the surviving sample, highest scores on the GHQ, and thus report of the most psychological dysfunction, came from the youngest age group, the 18 to 30 year old patients. Their scores were highest at 6 weeks (mean 28, median 24.5), at 6 months (mean 33.4, median 31) and 12 months (mean 30.7, median 33.5). The 31 to 43 year old group had lowest scores at 6 months (mean 19.1, median 14) but these scores increased again by 12 months (mean 22.8, median 22).

In group 4 (57-69 years) initial scores were relatively high (mean 26.4, median 22) but scores fell markedly by 12 months, at which time this group had the lowest scores of all the surviving patients (mean 14, median 11) indicating the best psychological function as measured by the GHQ. No statistically significant difference was found between age groups via Kruskal Wallis one way ANOVA.

The GHQ28 can be scored on four subscales: somatic symptoms, anxiety, social function and depressive symptoms. Subscale analysis added some new information: Group 4 (57 to 69 years) reported worst social function, via the social subscale at the 6 week follow-up (mean 12.6, median 11.0) while best social function was reported by Group 1 (18-30 years, mean 9.4, median 9) and Group 3 (44 - 56 years, mean 9.8, median 9). Scores on the anxiety subscale at 6 weeks were highest, indicating worst function, in the youngest age group (18-30 years, mean 8.0, median 7.0) and lowest in Group 3 (44-56 years, mean 5.1, median 4). Depression subscale scores at 6 weeks were also highest in the youngest age group (mean 3.8, median 1) and lowest in the oldest group (57-69 years, mean 1, median .00). The youngest age group recorded highest scores on the anxiety and depressive subscales at 6 months ("anxiety" mean 10.1, median 8, "depression" mean 7, median 8) while the oldest age group (57-69 years) recorded the lowest scores at 6 months ("anxiety" mean 4, median 2, "depression" mean 0.8, median .00) indicating least psychological dysfunction. At 12 months scores across the subscales appeared more equal though the youngest group continued to record higher scores for anxiety (mean 9.8, median 11.5) and depression (mean 6.2, median

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8) when compared with the oldest age group scores on anxiety (mean 2, median 1) and depression (mean .25, median .00).

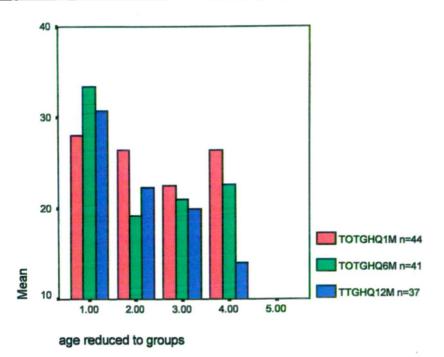
Kruskal Wallis one way ANOVA detected statistically significant difference between groups on the depression subscale at 6 months (Chi square = 9.36, p = 0.025); no other significant differences were found.

Multiple comparison tests were then carried out to see which groups actually differed. The Mean Rank Sums test was performed in preference to a series of Mann Whitney tests, to minimise the possibility of a Type I error (Siegel & Castellan 1988). Statistically significant difference was found between Group 1 (18-30 years) and Group 4 (57-69 years) (Chi square = 14.61, p < 0.05).

Scores on the Self Esteem scale were highest throughout the entire follow up in the youngest age group, Group 1. Scores were, at 6 weeks (mean 20.6, median 20.5) at 6 months (mean 20.8, median 21) and at 12 months (mean 19.7, median 20). These scores reflected the higher GHQ scores recorded by this group, indicating that low self esteem accompanied psychological dysfunction. Scores were lowest in the oldest patients (57-69 years) at 6 weeks (mean 12.4, median 15); scores were equally low in these plus the 44 to 56 year olds at 6 months, and again lowest in the 57 to 69 year olds at 12 months (mean 13.5, median 14.5), indicating best self esteem in the older groups. No statistically significant difference was found between groups via Kruskal Wallis one way ANOVA.

The similarity in patterns of scores for GHQ and SES is evident in Figures 8.iv and 8.v.

# Figure 8:iv: Mean GHQ scores by age group.



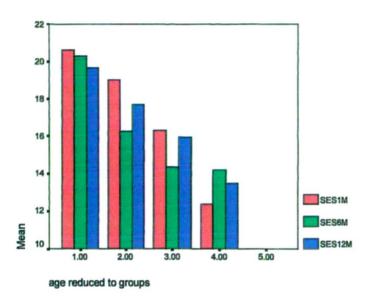
TOTGHQ1M = total GHQ28 scores at 6 weeks

TOTGHQ6M = total GHQ28 scores at 6 months

TOTGHQ12M = total GHQ28 scores at 12 months

Groups: 1 = 18-30, 2 = 31-43, 3 = 44-56, 4 = 57-69 5 = 70-82 (1patient, died before follow up commenced)





SES1M = total self esteem scores at 6 weeks SES6M = total self esteem scores at 6 months SES12M = total self esteem scores at 12 months Groups: 1 = 18-30, 2 = 31-43, 3 = 44-56, 4 = 57-69 5 = 70-82 years (1 patient, died before follow-up commenced).

Quite marked differences in scores on the IOES were evident, with the youngest age group scoring consistently highest - thereby reporting most by way of post traumatic stress symptoms - across all follow up points. The oldest age group (57 to 69 years)consistently scored lowest on the IOES, reporting fewest symptoms. By the 12 month follow up there was considerable difference in scores between the 18 to 30 year olds (mean 17.3, median 17.5) and the 57 to 69 year olds (mean 2, median 1.5). No statistically significant between group

differences were found via Kruskal Wallis one way ANOVA of total scores, although difference at six weeks approached significance (Chi Square 7.45, p<0.06).

The Impact of Event scale can also be scored on subscales for symptoms of intrusive thought ("Intrusion") and of avoidant behaviour ("Avoidance"). However examination of IOES subscales in relation to age group yielded very little new information beyond that provided by the initial total IOES scores, and no statistically significant differences were found.

## Length of stay in ICU

Exact lengths of stay in the unit were also quite diverse and were therefore grouped at intervals of three days to facilitate examination by subgroup. Five groups were designated and the frequency grouping was as follows:-

		COUNT					
Category	Description	Original	6 weeks	6 months	1yr		
1.	2-5 days	44	26	25	23		
2.	6-9 days	10	8	7	6		
3.	10-13 days	13	7	6	5		
4.	14-17 days	4	3	3	3		
5.	18 days or over	1	0	0	0		
Total		72	44	41	37		

### Table 8k Grouped frequency distribution, Length of Stay ICU.

These original categories contained small numbers, therefore categories were collapsed further to increase size. Three groups were designated, and the new frequency grouping was as follows:-

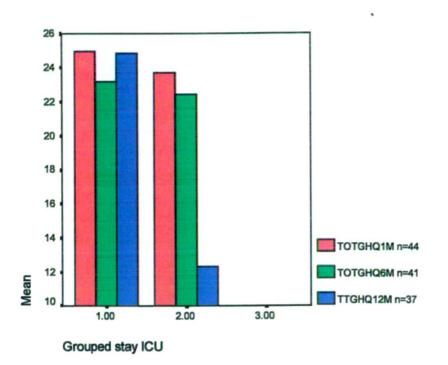
		COUNT					
Category	Description	Original	6 weeks	6 months	1yr		
1.	2-8 days	51	31	29	27		
2.	9-15 days	19	13	12	10		
3.	16-23 days	2	0	0	0		
Total		72	44	41	37		

Table 8 I: Grouped frequency distribution, Length of Stay ICU (collapsed categories).
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GHQ scores showed little between group difference at 6 weeks or at 6 months. At 12 months however a marked difference was evident with the shorter stay (2-8 days) group had higher scores (mean 24.85, median 22) than the longer stay (9-15 days) group (mean 12.3, median 9.5), although there was discrepancy in group size at 12 months as seen in the frequency grouping table above.

Mann Whitney testing demonstrated a statistically significant difference between groups at 12 months (Mann Whitney U = 60.5, 2-tailed p = 0.01). Subscales yielded no new information.

### Figure 8:vi: Mean GHQ scores by ICU stay group.



TOTGHQ1M = total GHQ28 scores at 6 weeks TOTGHQ6M = total GHQ28 scores at 6 months TOTGHQ12M = total GHQ28 scores at 12 months

Groups: 1 = 2-8 days, 2 = 9-15 days, 3 = 16-23 days (2 patients, died before follow-up commenced).

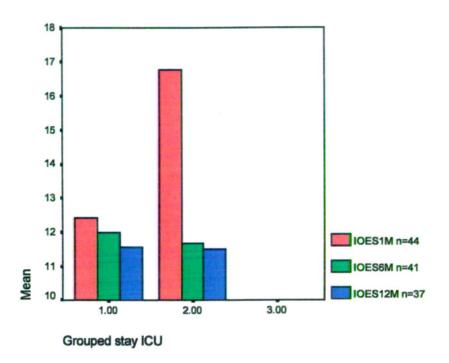
SES scores were also higher overall in the shorter stay group indicating poorer self-esteem. Little difference was evident at 6 weeks, but at 6 months the shorter stay group had higher scores (mean 17.24, median 18) than the longer stay group (mean 11.92, median 12). This level of difference endured at 12 months ( shorter stay group mean 18.4, median 17, longer stay group mean 11.8, median 12).

Mann Whitney U testing demonstrated a statistically significant difference between groups at 6 months (Mann Whitney U = 103, 2-tailed p = 0.04) and at 12 months (Mann Whitney U = 70.5, 2-tailed p = 0.03).

In contrast, IOES scores at 6 week follow up were lowest in the shorter stay group (mean 12.4, median 12) than in the longer stay group (mean 16.7, median 19.0) indicating fewest post traumatic stress symptoms in the shorter stay group. IOES scores levelled out between groups at 6 months and little difference was seen at 12 months.

Mann Whitney U testing demonstrated no statistically significant difference between groups, and subscales yielded no new information.

# Figure 8:vii: Mean Impact of Event scores by ICU stay group.



IOES1M = total Impact of Event score at 6 weeks IOES6M = total Impact of Event score at 6 months IOES12M = total Impact of Event score at 12 months

Groups: 1 = 2-8 days, 2 = 9-15 days, 3 = 16-23 days (2 patients, died before follow-up commenced).

## Length of stay in hospital.

Overall lengths of stay in the hospital were also grouped for subgroup analysis and the frequency grouping was as follows:-

		COUNT					
Category	Description	Original	6 weeks	6 months	1yr		
1.	Up to 25 days	32	16	16	15		
2.	26-50 days	29	22	20	19		
3.	51-75 days	8	4	4	2		
4.	76-100 days	2	1	0	0		
5.	101 days or over	1	1	1	1		
Total		72	44	41	37		

## Table 8m: Grouped frequency distribution, Length of Stay in Hospital,

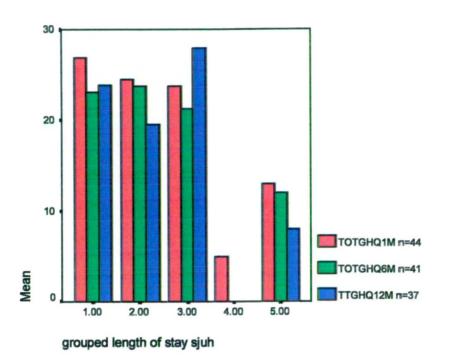
An attempt was made to collapse the groups further to increase size. However various attempts at different sized categories all resulted in the same very small numbers in the longest staying groups, therefore the groups as shown above remained.

Those patients who remained in hospital for shorter lengths of time recorded poorest psychological function via the GHQ at first follow up, and this endured at 6 months. Lowest GHQ score, indicating best function, was recorded by the 1 patient who had stayed in hospital for an extensive period. At final follow up, 12 months, the poorest report of psychological function via GHQ28 scores came from the small Group 3, stayers of 51 to 75 days (mean 28, median 28). Little new information emerged from subscale analysis.

Self esteem scores paralleled the pattern of the GHQ scores, with poor psychological function being accompanied by low self esteem. No statistically significant differences were evident for subgroups on either the GHQ or the Self esteem scale, when subjected to Kruskal Wallis one way ANOVA.

IOES scores at 6 week follow up were lowest in the longest staying patient, highest in Group 3, the 51 to 75 days group (mean 16.8, median 21). There was equivalence across all groups at 6 month follow up, then the pattern reversed and the longest staying patient recorded higher scores and thus more by way of PTSD symptoms, while the middle group, Group 3, changed from highest scoring to lowest scoring group (mean 5, median 5) though by this stage this was a very small group of 2 patients only. No significant between group differences were found via Kruskal Wallis one way ANOVA, and no new information was yielded by IOES subscale analysis.

### Figure 8:viii:Mean GHQ scores by hospital stay group.



TOTGHQIM = total GHQ28 score at 6 weeks TOTGHQ6M = total GHQ28 score at 6 months TOTGHQ12M = total GHQ28 score at 12 months

Groups:  $1 = \langle 25 \text{ days}, 2 = 26-50 \text{ days}, 3 = 51-75 \text{ days}, 4 = 76-100 \text{ days}$  (1 patient, died after 6/52 follow-up), 5 = 101 days or more.

### Admission severity scores

Admission severity was measured using the APACHE II score recorded on first day admission to the ICU. APACHE (Acute Physiological and Chronic Health Evaluation) scores measure illness severity using a system which assigns points according to derangement of a number of number of physiological variables (for a fuller explanation see Chapter Five). First day APACHE score is therefore a potentially useful measure of the degree of sickness of the individual patient, with higher figures indicating more severe illness.

Grouping of the APACHE admission severity scores was effected in intervals of 10 points allowing 4 groups, and the resulting frequency grouping was as follows:-

				COUNT					
Category 1.	Desc	cription	Original	6 weeks	6 months	1yr			
1.	Apa	che 1-10	10	7	7	7			
2.	"	11-20	40	20	19	16			
3.	"	21-30	17	12	11	10			
4.	"	31-40	5	5	4	4			
Total			72	44	41	37			

#### Table 8n : Grouped frequency distribution, Admission Severity.

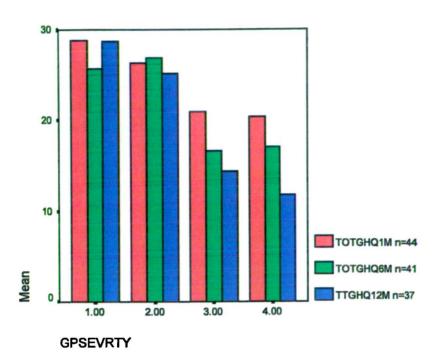
GHQ scores at first follow up were higher in Groups 1 and 2, the lowest Apache score groups (Group 1, mean 28.9, median 22, Group 2, mean 26.3, median 24). Scores were slightly lower in those with high Apache scores: that is the more severely ill the patient on admission the better the psychological function as measured by the GHQ at first follow up.

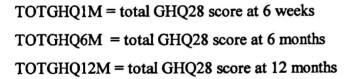
This pattern endured at 6 and 12 months, and by final follow up the difference was quite marked with those severely ill on admission recording significantly lower scores on the

GHQ28 (Group 3, mean 14.3, median 12, Group 4, mean 11.6, median 9.5) and Group 1, the least ill on admission, recording the highest scores (mean 28.7, median 24). The indication was that better psychological function was reported by those who had been sickest on admission. Statistical significance was found via Kruskal Wallis one way ANOVA for 12 months GHQ scores (Chi Square 7.98 p<0.05). Subscale analysis, however, produced very little extra information for this subgrouping.

Multiple comparison by way of the Mean Rank Sums test showed a statistically significant difference between Group 1 (Apache score 1-10) and Group 4 (Apache score 31-40) (Chi square = 18.98, p<0.05) and between Group 2 (Apache score 11-20) and Group 4 (Chi square = 16.92, p<0.05).







Groups: 1 = 1-10, 2 = 11-20, 3 = 21-30, 4 = 31-40 first day Apache score

Self esteem scores reflected the GHQ scores, with best self esteem in the higher APACHE Groups 3 and 4 (most severely ill on admission) and poorest self esteem in Group 1, those with low APACHE scores (least severely ill on admission). This pattern endured across the follow up period and by 12 month follow up the difference was most marked between Group 1 (mean 21.1, median 25) and Groups 3 (mean 11.3, median 14) and Group 4 (mean 11, median 11).

At all three follow up points Kruskal Wallis one way ANOVA detected significant between group difference - at 6 weeks ( Chi Square 10.32, p<0.008), at 6 months ( Chi Square 13.79 p<0.005) and at 12 months ( Chi Square 9.34, p<0.03.)

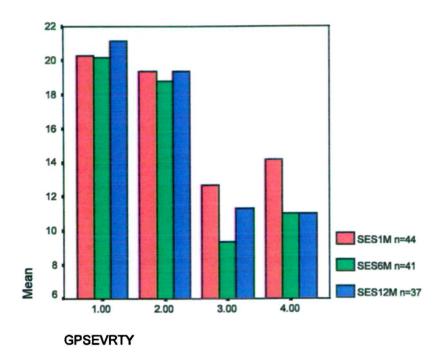
Multiple comparison by way of the Mean Rank Sums test showed statistically significant differences between groups as follows:-

SES scores at 6 weeks: statistically significant difference was found between Group 1 (Apache 1-10) and Group 3 (Apache 21-30) (Chi square = 16.06, p<0.05).

SES scores at 6 months: statistically significant difference was found between Group1 (Apache 1-10) and Group 3 (Apache 21-30) (Chi square = 15.2, p<0.05).

SES scores at 12 months: statistically significant difference was found between Group 1 (Apache 1-10) and Group 3 (Apache 21-30) (Chi square = 11.90, p<0.05).

#### Figure 8:x : Mean Self esteem scores by admission severity



SES1M = self esteem score at six weeks

SES6M = self esteem score at six months

SES12M = self esteem score at twelve months

Groups 1 = 1-10, 2 = 11-20, 3 = 21-30, 4 = 31 - 40 first day Apache score

At initial follow up IOES scores were lowest in Group 1, the lowest APACHE score group (mean 10.6, median 4) and higher in the other three groups, indicating fewest post traumatic stress symptoms in those who were least severely ill on admission. At 6 months highest IOES scores were displayed by moderate APACHE score Group 2,(mean 14.8, median 15). At 12 months the findings altered somewhat, and patients from Groups 1 and 2 APACHE score groups (patients who were least severely ill on admission) recorded highest IOES scores, thus

indicating most symptoms of post traumatic stress, while those from Group 4, who had been the most severely ill on admission, had reduced their scores (mean 9, median 6) indicating that symptoms of PTSD were abating. No statistically significant differences were detected via Kruskal Wallis, and the intrusion and avoidant subscale analysis did not yield any extra information.

#### Patient recall of ICU

Recall for the experience was recorded as full, vague or entirely absent according to the patient at ward interview. The majority (38 patients) had some hazy recall of the ICU and the experience therein. 14 patients were able to recall quite accurately the experience, while 20 patients claimed to have no recall whatsoever of the period in ICU.

The frequency grouping was as follows:-

			COUNT	
Description	Original	6 weeks	6 months	1yr
No recall	20	13	12	9
Vague recall	38	24	23	22
Full recall	14	7	6	6
Total	72	44	41	37

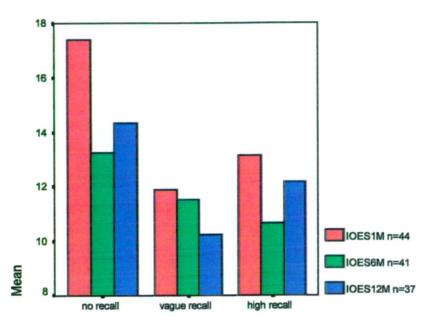
#### Table 8 o: Frequency distribution, Recall.

Few between group differences emerged via either the GHQ and its subscales, or the SES. The "vague" recall group consistently had lowest GHQ scores (indicating best psychological function) with the most marked difference being at 12 months (mean 18.4, median 13). This pattern was reflected in the self esteem scores where again the "vague" recall group had

lowest scores indicating better self esteem. No statistically significant differences were detected via Kruskal Wallis one way ANOVA.

The IOES scores offered the most discrimination with regard to recall. At 6 weeks the highest IOES scores, indicating most symptoms of post traumatic stress, were reported by the ∛no recall group (mean 17.4, median 23), lowest scores by the "vague" recall group (mean 11.9, median 10.5). The "no recall" group had a slight reduction in scores over the follow up period. The "high" recall group reported slight reduction in symptoms at 6 months but scores were creeping up by 12 months and the "high" recall group had the highest median score (mean 12.2, median 13.5) though the "no recall" group retained the highest mean score (mean 14.3, median 9). IOES subscales allowed little by way of further differentiation, and no statistically significant differences were detected using Kruskal Wallis one way ANOVA.

## Figure 8:xi: Mean Impact of event scores by recall.



patient recall of time on icu

IOES1M = Impact of event score at 6 weeks IOES6M = Impact of Event score at 6 months IOES12M = Impact of Event score at 12 months

#### **Communication**

Allied to recall is the issue of communication, specifically patients' perceptions of communication with the ICU staff. At ward interview subjects were asked one question: "When you tried, were you able to make most people understand what you wanted?" Communication was then recorded as good or poor. The frequency grouping was as follows:-

			COUNT		
Description	Original	6 weeks	6 months	1yr	_
Poor	45	31	29	25	_
Good	27	13	12	12	
Total	72	44	41	37	

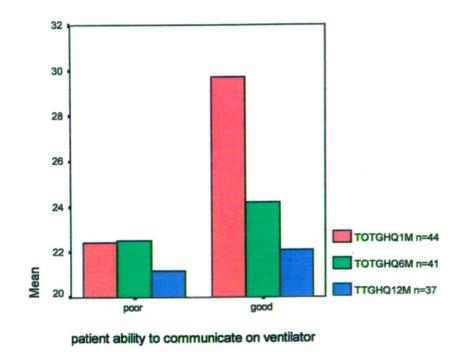
Table 8p: Frequency distribution, Communication.

The "good" communication group recorded highest GHQ scores, indicating poorer psychological function, across the entire follow up period. The difference was most marked at the 6 week follow up where the "poor" group had lower scores (mean 22.5, median 21) and the "good" group reported higher scores (mean 29.7, median 27). Mann Whitney U test produced a statistically significant difference between groups for the GHQ28 at the 6 weeks follow up (U = 120, 2 tailed p<0.04). Mann Whitney U was the test of choice for this subgroup. This test is a non-parametric alternative to t-testing, and compares distribution of an ordinal level variable between two non-related groups.

The scores on the Self esteem scale reflected this across all follow up points, with higher scores (and thus lower self esteem) in the "good" communication group. No statistically significant differences were detected using Mann Whitney U.

The 6 week IOES scores were similar for both groups, but for the "poor" group the scores decreased at 6 months then again at 12 months, indicating gradually abating PTSD symptoms. In the "good" group IOES scores did not show this gradual diminution and in fact rose at 12 months (mean 14.9, median 16), to a level which was higher than the initial 6 week scores. No statistically significant differences were detected via the Mann Whitney test.

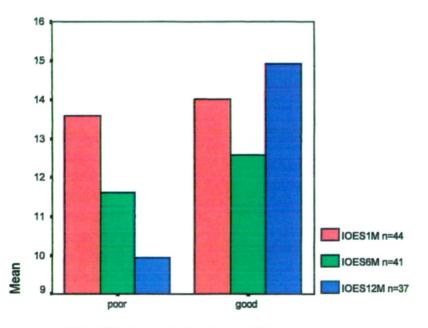
Neither set of subscales - for the GHQ28 or the IOES - yielded any additional information.





TOTGHQ1M = total GHQ28 scores at 6 weeks TOTGHQ6M = total GHQ28 scores at 6 months TOTGHQ12M = total GHQ28 scores at 12 months

# Figure 8: xiii: Mean Impact of Event scores by communication.



patient ability to communicate on ventilator

IOES1M = Impact of Event scores at 6 weeks IOES6M = Impact of Event scores at 6 months IOES12M = Impact of Event scores at 12 months

# Social support.

Social support was categorised according to the support available in the patient's home or nearby. The frequency grouping was as follows:-

	COUNT							
Description	Original		6 weeks		6 months		1yr	
Lives with next of kin	52		33		30		27	
Next of kin nearby		15		9		9		8
Friends/neighbours nearby		1		0		0		0
Minimal support	4		2		2		2	
Total	72		44		41		37	

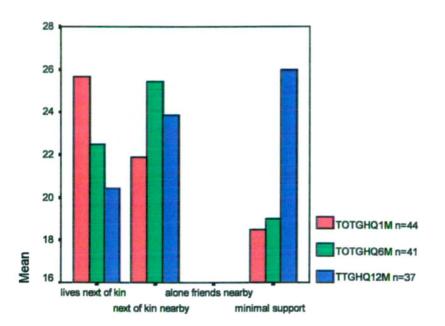
### Table 8q: Frequency distribution, Social Support

Those living with next of kin had highest GHQ scores at 6 weeks (mean 25.7, median 24) and the 2 patients living alone with minimal support recorded lowest GHQ scores (mean 18.5, median 18.5). For those living with next of kin however there was a gradual decrease in GHQ score over the follow up period indicating gradual improvement in psychological function.

Those living alone with next of kin living nearby showed an increase in GHQ scores ( and thus diminution of function) from 6 weeks to 6 months, and at 12 months this group had higher scores (mean 23.9, median 20.5) than they had recorded at 6 week follow up, indicating a worsening of function.

The group living alone with minimal support showed a steady decrease in wellbeing over the 12 months, as reflected by the GHQ28 scores, and this group recorded highest GHQ scores at 12 months (mean 26, median 26) - though it must be noted that this was a very small group of 2 patients. No additional information emerged from analysis of the GHQ28 subscales, and no statistically significant difference was found between groups via Kruskal Wallis one way ANOVA.





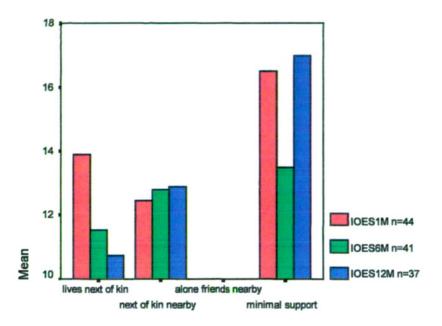
social support anticipated following discharge

TOTGHQ1M = total GHQ28 scores at 6 weeks TOTGHQ6M = total GHQ28 scores at 6 months TOTGHQ12M = total GHQ28 scores at 12 months "alone, friends nearby" group - 1 patient, died before follow-up commenced.

Self esteem kept pace with the GHQ28 findings. Those living with next of kin reported overall gradually improved self esteem over the year, while those with next of kin nearby recorded little difference in mean scores, though the median had fallen from 21 at 6 weeks to 16.5 at 12 months. Patients living alone with minimal support recorded increasing scores over the follow up period, mean and median, indicating worsening self esteem by the end of the year . No statistically significant between group differences were detected via Kruskal Wallis one way ANOVA.

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Symptoms of post traumatic stress were greatest in the (very small) minimal support group. For these patients IOES scores reduced at 6 months, but by 12 months IOES scores were higher (mean 17, median 17) than at the initial follow-up indicating a worsening of posttraumatic stress symptoms by the end of the first year. The apparently better supported groups on the other hand fared better: those living with next of kin reported IOES scores which reduced gradually over the follow up period indicating abatement of post traumatic stress symptoms as the year passed. For the group with more moderate support, that is living alone but with next of kin nearby, the median score fell from 14 at 6 weeks to 7 at 12 months. IOES subscale analysis added no new information, and no statistically significant differences between any groups were found using Kruskal Wallis one way ANOVA.



### Figure 8:xv: Mean Impact of Event scores by social support.

social support anticipated following discharge

IOES1M = Impact of Event scores at 6 weeks IOES6M = Impact of Event scores at 6 months IOES12M = Impact of Event scores at 12 months

\*"alone, friends nearby" group - 1 patient, died before follow-up commenced.

## Sleep

At ward interview patients were asked to assess the quality of the sleep obtained while on the ICU. Sleep was ranked in three groups and patients assessed the situation as "feels he/she slept well", "feels he/she got a reasonable amount of sleep" or "feels he/she slept poorly". This ranking clearly relied on subjectivity but it did offer a picture of patients' own

own perceptions of sleep in the ICU compared to their usual sleep, thus identifying those who perceived sleep disturbance. The frequency grouping was as follows:-

			COUNT	
Description	Original	6 weeks	6 months	1yr
Slept poorly	32	20	19	17
Slept reasonably	35	23	21	19
Slept well	5	1	1	1
Total	72	44	41	37

# Table 8r: Frequency distribution, Sleep.

These groups resulted in very small numbers in the "slept well" category, therefore the categories were collapsed to increase size of groups. The resulting two groups were as follows:-

## Table 8s: Frequency distribution, Sleep (collapsed categories).

	<u></u>		COUNT		
Description	Original	6 weeks	6 months	1yr	
Slept poorly	32	20	19	17	
Slept reasonably or well	40	24	22	20	
Total	72	44	41	37	<u> </u>

Little difference was evident between groups for GHQ scores at any of the three follow-up points. The greatest difference was at 12 months when the "slept poorly" group had a higher median score (19) than the "slept reasonably or well" group (median 15.5). No statistically significant differences were detected via Mann Whitney U testing, and GHQ subscales showed no significant differences.

The SES scores were similarly alike reflecting the findings via the GHQ scores. Again at 12 months scores were slightly higher in the "slept poorly" group (mean 17.1, median 16) than in the "slept reasonably or well" group (mean 16.3, median 15) indicating slightly lower self esteem. No statistically significant differences were detected via Mann Whitney U testing.

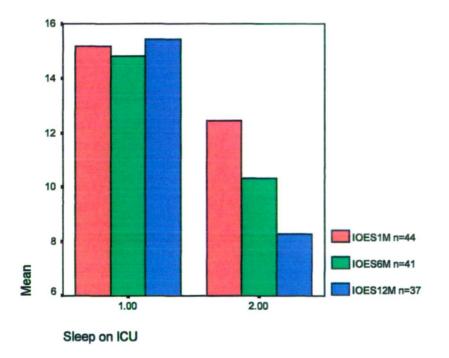
Some difference was however discernible via the IOES scores. Scores were higher in the "slept poorly" group at 6 weeks (mean 15.2, median 14.5) than in the "slept reasonably or well" group (mean 12.5, median 11.0). This pattern endured at 6 months, and by 12 months the difference was most evident with a higher score for the "slept poorly" group (mean 15.4, median 15) as compared with the "slept reasonably or well" group (mean 8.3, median 3.5). Mann Whitney U testing found no statistically significant differences between IOES scores at 6 weeks or 6 months. Difference between groups came extremely close to significance at 12 months

(Mann Whitney U = 106, 2-tailed p = 0.052).

The subscales of the IOES were examined. At 6 weeks and 6 months no statistically significant differences were detected. At 12 months difference was noted with a higher score on the "intrusion" subscale for the "slept poorly" group (mean 8.2, median 6) than the "slept reasonably or well" group (mean 4.6, median 1.5). This was repeated in the "avoidance" subscale with a higher score for the "slept poorly" group (mean 7.2, median 7)) than for the "slept reasonably or well" group (mean 3.7, median 1).

Mann Whitney U testing detected a statistically significant difference between groups for the "intrusive" subscale at 12 months (Mann Whitney U = 106, 2-tailed p = 0.049) but not for the "avoidance" subscale.

## Figure 8:xvi: Mean Impact of event scores by sleep.



- IOES1M = total Impact of Event score at 6 weeks
- IOES6M = total Impact of Event score at 6 months
- IOES12M = total Impact of Event score at 12 months

Groups: 1 = "slept poorly", 2 = "slept reasonably or well".

### **Occupational Classification**

The frequency distribution for the original sample was as follows:-

		COUNT					
Category	Description	Original	6weeks	6months	1yr		
1.	Professional	8	5	5	5		
2.	Managerial/technical	15	10	9	8		
3.	Clerical/minor supervisory	17	12	11	9		
4.	Semi-skilled manual	26	15	14	13		
5.	Unskilled manual	4	0	0	0		
6.	Full time student	2	2	2	2		
Total		72	44	41	37		

#### Table 8t: Frequency distribution, Occupational Classification.

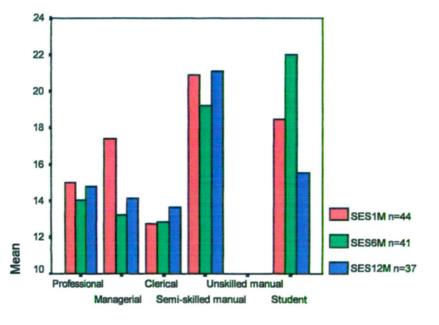
Some differences between occupational classes were discernible on inspection of the score totals: for the GHQ28 semi-skilled manual scored highest, (mean 29.1, median 25) indicating poorest psychological function, while clerical/minor supervisory groups scored lowest (mean 20, median 22) indicating better function, though as the figures indicate there was no huge difference. At 6 months the highest scores were recorded by the 2 full time students (mean 27.5, median 27.5) indicating worst psychological function. The professional group (5 patients throughout follow up period) showed a worsening of function over the 12 months and by final follow up these patients had the highest GHQ scores of all the groups (mean 26.8, median 22). No differences emerged via the GHQ subscales, and no statistically significant difference emerged using Kruskal Wallis one way ANOVA.

SES scores indicated lowest self esteem in semi-skilled manual and student classes, in parallel with poor psychological function, and best self esteem in the clerical/minor supervisory group.

The students recorded highest scores at 6 months (mean 22, median 22) indicating low self esteem in parallel with their high GHQ scores, but this improved somewhat by 12 months (mean 15.5, median 15.5). No statistically significant differences were found for self esteem scores, although at 6 months, where the students recorded noticeably higher scores, the results approached significance (Chi Square 9.09, p<0.06).

Scores on the IOES were highest in the small student group at 6 week follow up, (mean 20, median 20) and in the semi-skilled manual group (mean 17.1, median 23) indicating most post traumatic stress symptoms for these groups. Lowest IOES scores were recorded by the clerical / minor supervisory group (mean 10.7, median 11.5) and managerial/technical group (mean 11.9, median 10.5), the groups which had reported best psychological function and self esteem. At 6 months IOES scores were still highest in the students and the semi-skilled manual group, and at 12 months the semi-skilled manual group continued to record high scores (mean 17, median 17) while in all the other occupational groups scores had reduced to relatively low levels indicating reduction of PTSD symptoms. The IOES subscales yielded no additional information and Kruskal Wallis one way ANOVA produced no statistically significant results

# Figure 8:xvii: Mean self esteem scores by occupational classification.



class by occupation

\* High scores represent low self esteem.

SES1M = total self esteem score at 6 weeks SES6M = total self esteem score at 6 months SES12M = total self esteem score at 12 months "Unskilled manual" - 4 patients, died before follow-up commenced.

## Mode of admission.

Mode of admission to ICU was categorised thus:-

- 1. Electively admitted with preparation
- 2. Admitted conscious from a ward
- 3. Admitted unconscious from a ward
- 4. Admitted conscious from Accident and Emergency (A/E) department
- 5. Admitted unconscious from Accident and Emergency (A/E) department
- 6. Unplanned admission straight from Operating Theatre (OT).

The original frequency distribution was as follows:-

## Table 8u: Frequency distribution, Mode of Admission

Category			COUNT				
	Description (	Driginal	6 weeks	6 months	1yr		
1.	Elective	29	23	22	20		
2.	Conscious from ward	4	1	1	1		
3.	Unconscious from ward	16	4	3	2		
4.	Conscious from A&E	5	2	2	2		
5.	Unconscious from A&I	E 15	10	9	8		
6.	Unplanned from O.T.	13	4	4	4		
Total		72	44	41	37		

A&E = Accident and emergency department

O.T. = Operating theatre

These original categories contained small numbers, therefore categories were collapsed further to increase size. Four groups were designated, and the new frequency grouping was as follows:-

			COUNT		
Category	Description	Original	6 weeks	6 months	1 yr
1.	Elective	29	23	22	20
2.	Conscious(Wd/A&E)	9	3	3	3
3.	Unconscious(Wd/A&E)	21	14	12	10
4.	Unplanned from O.T.	13	4	4	4
Total	· <u> </u>	72	44	41	37

#### Table 8v: Frequency distribution, mode of admission (collapsed categories).

Wd = Ward

A&E = Accident and emergency department

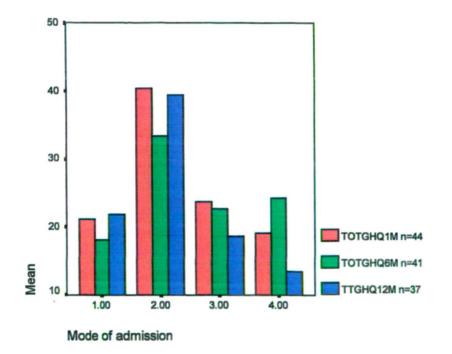
O.T. = Operating theatre

The majority of patients was admitted electively, with the second largest group being those admitted unconscious from either the ward or the Accident and Emergency department Smallest group was patients admitted conscious to the unit, 9 patients originally which was reduced to a small group of only 3 by the time follow-up commenced.

GHQ scores were highest at 6 weeks in the "conscious" group (mean 40.3, median 31) and lowest in the "unplanned from OT" group (mean 19, median 20.5). Scores remained highest in the "conscious" group at 6 months (mean 33.3, median 31) and at 12 months (mean 22, median 25). By 12 months the "unplanned from OT" group had noticeably lower scores

(mean 13.5, median 10) than any other group. The "elective" group showed little reduction in scores across all three follow-up points, while the "unconscious" group showed gradual reduction from 6 weeks (mean 27.5, median 24.5) to final follow-up at 12 months (mean 18.7, median 16.5). No new information was added by the GHQ subscales.

Kruskal Wallis one way ANOVA detected no statistically significant difference between groups.



#### Figure 8: xviii: Mean GHQ scores by mode of admission.

TOTGHQ1M = total GHQ28 score at 6 weeks TOTGHQ6M = total GHQ28 score at 6 months TOTGHQ12M = total GHQ28 score at 12 months SES scores reflected the GHQ findings, with highest scores in the small "conscious" group at 6 weeks (mean 22, median 25) indicating lower self esteem in this group. Lowest SES scores at 6 weeks were seen in the "unplanned from OT" group (mean 13.3, median 15.5). At 6 months the "conscious" group remained highest scorers (mean 22.3, median 25) and this endured at 12 months. Lowest scores throughout the follow-up period were seen in the "unplanned from OT" group.

Kruskal Wallis one way ANOVA detected no statistically significant between group difference for SES scores at any point.

Highest IOES scores at 6 weeks were seen in the small "conscious" group (mean 21.7, median 25), indicating most symptoms of PTSD in this group, while lowest scores were seen in the "elective" group (mean 9.3, median 4). The "unconscious" group also had fairly high scores (mean 19.3, median 21) at this first follow-up point. At 6 months the "elective" group remained lowest scoring (mean 10.2, median 7.5) and the "conscious" group the highest scoring (mean 16.3, median 17). By 12 months lowest scores were seen in the "unconscous" group (mean 9.3, median 3) demonstrating a considerable reduction in scores over the follow-up period. The "elective" group remained reasonably low scoring at 12 month follow-up. Highest scores persisted in the "conscious" group (mean 18.3, median 17) and there was also a slight increase in scores for the "unplanned from OT" group indicating worsening of PTSD symptoms between 6 and 12 months.

Kruskal Wallis one way ANOVA found a statistically significant between group difference in the 6 weeks IOES scores (Chi square = 10.4, p = 0.02) but not in 6 month or 12 month scores.

Multiple comparison by way of Mean Rank Sum testing, however, did not detect any statistically significant difference between any groups. The "conscious" patients comprised a

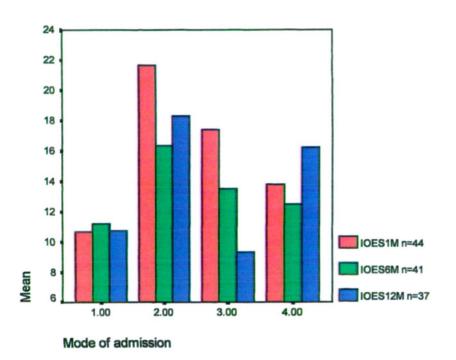
very small group, as seen in the Frequency Grouping, and it was considered that the 6 weeks difference detected by Kruskal Wallis testing may be spurious.

Subscales for the IOES were also examined. At 6 weeks scores were lower on both subscales in the "elective" group ("intrusion" mean 4.7, median 3, "avoidance" mean 4.5, median 3). Scores were highest in the small "conscious" group ("intrusion" mean 9, median 12, "avoidance" mean 12.7, median 13). Subscale scores were consistently higher in the "conscious" group across all the follow-up points. At 12 months the "conscious" subgroup scores were "intrusion" mean 10.7, median 8, "avoidance" mean 7.7, median 9. The lowest scores at 12 months were recorded by the "unconscious" group ("intrusion" mean 4.1, median 2, "avoidance" mean 5.2, median 1.5).

Kruskal Wallis one way ANOVA testing between subscales detected statistically significant difference at 6 weeks for the "avoidance" subscale (Chi square = 13.91, p = 0.03), but no other significant differences were found.

Multiple comparison testing via Mean Rank Sum testing detected no statistically significant difference between groups, implying again that the Kruskal Wallis findings may be spurious.

# Figure 8:xix: Mean Impact of event scores by mode of admission.



IOES1M = impact of event scores at 6 weeks IOES6M = impact of event scores at 6 months IOES12M = impact of event scores at 12 months

Groups: 1 =elective, 2 =conscious (Wd/A&E), 3 =unconscious (Wd/A&E), 4 =unplanned O.T.

Wd = Ward, A&E = Accident and emergency, O.T. = Operating theatre.

#### Illness - indication for admission

The frequency distribution was as follows:-

#### Table 8w: Frequency distribution, Indication for Admission.

	COUNT			
Category Description	Original	6 weeks	6 months	1yr
1. Respiratory disease	15	7	7	7
2. Cardiovascular disease	2	1	0	0
3. Trauma	7	4	4	3
4. Metabolic/endocrine disease	6	4	3	2
5. Transplant surgery	17	14	13	13
6. Planned surgery	15	10	10	8
7. Unplanned surgery	10	4	4	4
Total	72	44	41	37

The GHQ scores recorded by the trauma group were noticeably higher than other groups, commencing at 6 weeks (mean 45.5, median 55.5) and not reducing greatly by 12 months (mean 38, median 53) though the group had reduced in size to 3 patients by the final follow up point. Trauma patients remained the group with overall greatest dysfunction as assessed by the GHQ. Lowest GHQ scores were recorded at 6 weeks by the transplant group (mean 18.4, median 22) and the respiratory disease group (mean 19, median 16). The respiratory group then showed a slight increase in score (indicating decrease in function) at 6 months, followed by a decreased score at 12 months. The GHQ scores for the transplant group altered at 6 months (mean 20.5, median 17) and maintained this kind of level at 12 months (mean 21.8, median 17), indicating no further improvement in function at this stage.

In patients admitted for unplanned surgery GHQ scores were initially quite high (mean 28.3, median 25), but the scores had fallen considerably by 12 months, (mean 15, median 14.5) as might be predicted in a group which has experienced an acute and sudden episode of illness which may be followed by fairly rapid recovery.

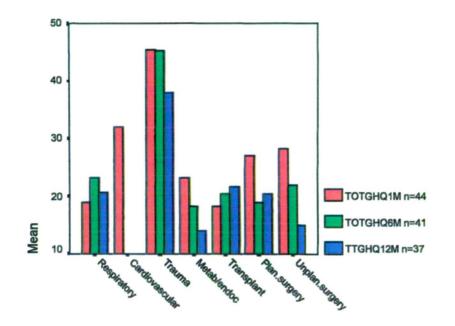
The GHQ subscales were examined and some further difference was noted. At 6 weeks highest depression subscale score was recorded by the trauma group (mean 9.5, median 10.5) and lowest by the transplant group (mean 0.43, median 0). Depression score had increased at 6 months for the trauma group (mean 11.5, median 13.5) and had increased very slightly in the transplant group (mean 0.69, median 0). The lowest score was in the small metabolic/endocrne group (mean 0.33, median 0). At 12 months trauma patients maintained the highest depression subscale score (mean 9, median 10) and the very small metabolic/endocrine group the lowest (mean 0, median 0). The transplant patients had increased their depression scores again (mean 3, median 0) indicating more depressive symptoms at 12 months than at the initial follow-up.

Kruskal Wallis one way ANOVA of the GHQ28 subscales identified a between groups difference for the depression subscale at both 6 weeks (Chi square 12.6429, p<0.03) and 6 months (Chi square 11.3207, p<0.05).

Multiple comparison by way of Mean Rank Sum testing showed statistically significant difference between groups as follows:-

GHQ depression subscale at 6 weeks: significant difference between Group 3 (trauma) and Group 5 (transplant surgery) (Chi square = 18.9, p<0.05).

GHQ depression subscale at 6 months: significant difference between Group 3 (trauma) and Group 5 (transplant surgery) (Chi square = 17.7, p<0.05).





Indication for admission

TOTGHQ1M = total GHQ28 score at 6 weeks TOTGHQ6M = total GHQ28 score at 6 months TOTGHQ12M = total GHQ28 score at 12 months "Cardiovascular disease" - 2 patients, 1 died before follow-up commenced, 1 died following 6/52 follow-up.

Scores on the Self esteem scale were highest at 6 weeks in the trauma group (mean 24.3, median 27), indicating lowest self-esteem. The group's mean scores remained highest throughout the follow-up period. The lowest SES scores at 6 weeks came from the transplant group (mean 14.8, median 15.5) and the respiratory disease group (mean 15.3, median 13) indicating best self esteem in these two groups. For the transplant patients SES scores had not

improved at 12 months (mean 16.4, median 15) while for the metabolic/endocrine group and the unplanned surgery group scores had diminished indicating gradual improvement in self esteem over the year. Kruskal Wallis one way ANOVA produced no significant differences between groups.

IOES scores showed some discrimination. Highest scores at 6 weeks were recorded by trauma patients (mean 26.8, median 25.5) indicating most symptoms of post traumatic stress in this group (though it is allowed that the ICU experience may well be enmeshed with the initial trauma despite every effort methodologically to minimise this). Lowest IOES scores at 6 weeks were recorded by the transplant group (mean 9.6, median 7.5) and the planned surgery group (mean 8.7, median 4). Transplant patients recorded an increase in IOES scores at 6 months, but these fell again at 12 months. In all the groups but one IOES scores had decreased by 12 months from their initial 6 weeks levels, indicating that symptoms of PTSD were diminishing by the end of the year. The exception was the planned surgery group where scores were higher at 12 months (mean 13, median 9) indicating that symptoms were in fact more prevalent at this time than at initial follow-up. Overall trauma patients showed worst IOES scores; Kruskal Wallis one way ANOVA produced statistically significant differences between groups at 6 weeks ( Chi square 12.6318, p< .0493) but not at 6 nor 12 months.

Multiple comparison by way of Mean Rank Sum testing showed statistically significant difference between Group 3 (trauma) and Group 6 (planned surgery) (Chi square = 18.6, p<0.05).

In analysis of the IOES subscales, a difference was apparent on the avoidant subscale where the trauma group had highest scores at 6 weeks (mean 13.75, median 12.5); low scores were seen both in the transplant group (mean 4.29, median 3) and the planned surgery group (mean 4.7, median 1.5). The trauma group had notably higher scores on this subscale across the follow-up period and by 12 months their scores had reduced by only a small amount (mean 11.67, median 12). A statistically significant between groups difference was detected by Kruskal Wallis one way ANOVA at 6 weeks follow-up (Chi square 13.36, p<0.02).

Multiple comparison by way of Mean Rank Sum testing confirmed statistically significant difference between Group 3 (trauma) and Group 6 (planned surgery) on the IOES "avoidance" subscale (Chi square = 18.6, p<0.05).

## <u>Sex</u>

Sex distribution was as follows:-

#### Table 8x: Frequency distribution, Sex

			COUNT	
Sex	Original	6 weeks	6 months	1yr
Male	50	30	28	25
Female	22	14	13	12
Total	72	44	41	37

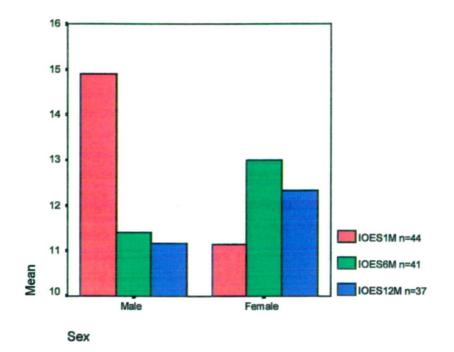
Total GHQ 28 scores were reduced for both sexes by the end of 12 months. Initially females recorded slightly higher scores (mean 25, median 23) than males (mean 24.4, median 22.5), a difference which became even more minimal at 6 months. At 12 months however mean GHQ28 scores were higher in males (mean 22.9, median 20) than in females (mean 18.4, median 12.5), indicating worse psychological function in males, though this difference did not reach statistical significance when subjected to Mann Whitney U analysis.

On examining the GHQ28 subscales, at 6 weeks women reported more physical dysfunction while men were more likely to record more depressive symptoms. This pattern endured at 6 months and by 12 months it was noted that men reported more dysfunction overall via all subscales. Men's continued higher depression scores were accompanied by greater physical, anxiety and social dysfunction scores, though none of these differences reached statistical significance.

Both sexes showed a rise in self-esteem at 6 months followed by a very slight reduction at the final 12 month point, differences were minimal and no statistically significant results emerged from Mann Whitney U testing.

Report of post traumatic stress symptoms via the IOES at 6 weeks was more prevalent in males (mean 14.9, median 13.5) than in females (mean 11.1, median 9) though this was not statistically significant. However in males IOES scores fell steadily over the 12 month followup indicating gradual reduction in symptoms, while in females IOES scores increased from 6 weeks to 6 months but had diminished again by the 12 month follow up. By the 12 month follow up there was a difference of 1 point between males (mean 11.2, median 8) and females (mean 12.3, median 7). Analysis via the subscales of the IOES - which measure avoidant behaviour and intrusive thought - enlarged the picture a little. At 6 weeks both groups of symptoms were more prevalent in men, but it was noticeable that women reported intrusive thought yet adopted little avoidant behaviour. At 6 months avoidance had begun in women accompanied by greater intrusive thought, and by 12 months both areas were prevalent in women while men were left with residual intrusive thought.

No statistically significant difference was detected via Mann Whitney U testing.



# Figure 8:xxi: Mean Impact of event scores by sex .

IOES1M = total Impact of Event score at 6 weeks IOES6M = total Impact of Event score at 6 months IOES12M = total Impact of Event score at 12 months

# Presence of relatives

The ICU involved in the study has some designated accommodation where the relatives of critically ill patients may stay. Distribution was as follows:-

			COUNT	
Relatives resident	Original	6 weeks	6months	1yr
Yes	16	7	7	6
No	56	37	34	31
Total	72	44	41	37

## Table 8y: Frequency distribution, Relatives Resident.

Little by way of difference was detected on examining the scores for each group, though those whose relatives had been resident had lower GHQ scores at 12 months (mean 15.2, median 10.5) than those whose relatives had not been resident (mean 22.7, median 20), indicating better psychological function in the patients whose relatives had stayed on ICU. This group also recorded lower SES scores indicating better self esteem, and also lower IOES scores at 6 weeks indicating less in the way of post traumatic stress symptoms. Mann Whitney U test revealed no statistically significant between group differences however and subscale analyses added no new information.

# Administration of muscle relaxants

A small number of patients received muscle relaxants (drugs which induce paralysis) while undergoing ventilation. The distribution was as follows:-

			COUNT	
Muscle relaxants	Original	6 weeks	6months	1yr
Yes	9	3	3	3
No	63	41	38	34
Total	72	44	41	37

#### Table 8z: Frequency distribution, Muscle relaxants.

In the surviving sample GHQ scores were higher at 6 weeks in the (very much larger) nonparalysed group (mean 25.0, median 24) than in the group of 3 patients which did receive the muscle relaxant or paralysing drugs (mean 19.3, median 22) indicating poorer psychological function. By 12 months these had levelled in the non-paralysed group to a mean of 21.8, median 17.5 and in the paralysed group to a mean of 17.3, median 20. No statistically significant difference detected by Mann Whitney U test.

SES scores showed no great differences in self esteem.

IOES scores did show some differentiation even allowing for the discrepancy in group size. Scores were consistently lower in the paralysed group indicating fewer symptoms of PTSD, the scores at 12 months were noticeably lower in those who received the drugs (mean 1.0, median 0) than in those who had not (mean 12.5, median 8.5).

Mann Whitney U testing demonstrated statistically significant difference in the 12 month IOES scores (Mann Whitney U = 15.5, p<0.05). Subscale analysis yielded no additional information however.

Cancer as part of diagnosis.

Distribution of cancer as part of the original problem was as follows:-

#### Table 8a: Frequency distribution, Cancer.

			COUNT		
Cancer	Original	6 weeks	6months	1yr	
Yes	19	13	12	10	
No	53	31	29	27	
Total	72	44	41	37	

Scores for this subgrouping showed little difference on the GHQ or its subscales, with both groups showing a slight decrease in scores over the follow up period. No statistically significant differences were detected via Mann Whitney U testing.

SES scores were slightly higher in cancer patients at 6 weeks and 6 months indicating lower self esteem, but again no statistically significant difference emerged via Mann Whitney U.

IOES scores however were markedly different, particularly at 6 weeks where the scores were higher in the non-cancer group (mean 15.9, median 14) than in the cancer group (mean 8.5, median 4). This endured at 6 months where scores remained higher in the non-cancer group (mean 13.7, median 12) than in the cancer group (mean 7.6, median 2). The IOES scores for the two groups began to level out at 12 months. Analysis via Mann Whitney U found a statistically significant difference for the IOES scores at six weeks, (Mann Whitney U= 73.5,

p < 0.04), though no significant difference was detected at six or twelve months. Analysis of the IOES subscales did not add any new information.

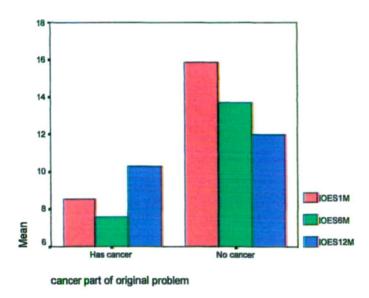


Figure 8: xxii: Mean Impact of event scores by cancer.

IOES1M = total Impact of Event score at 6 weeks IOES6M = total Impact of Event score at 6 months IOES12M = total Impact of Event score at 12 months

## Coincidental life events

Occurrence of other life events occurring in the follow up period, which were considered significantly stressful by the participants, was recorded along with the final set of assessment scores. Distribution was as follows:-

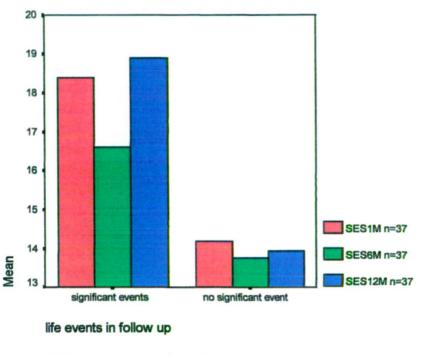
## Table 8β: Frequency distribution, Life events.

Life events	Final count	
Yes	20	
No	17	
Total	37	

Comparison of scores between these two groups showed little differences by way of GHQ scores although scores were slightly higher at 12 months is the group who did report life events (mean 22.1, median 19.5) than in the group who reported none (mean 20.8, median 13). Subscales showed no difference, and no statistically significant results were obtained via Mann Whitney U testing.

SES scores at 6 weeks did appear higher in the group which had reported life events (mean 18.4, median 19.5) than in the group which had not (mean 14.2, median 15) and this difference endured across the follow up period indicating lower self esteem in the group which had experienced other life events during the year. However these differences did not reach statistical significance.

# Figure 8:xxiii: Mean Self esteem scores by life events.



High scores represent low self esteem.

IOES scores were not markedly different at 6 weeks; at 6 months those who had reported life events had higher scores (mean 13.1, median 14.5) than those who had not (mean 11.5, median 9) indicating worse PTSD symptoms in the former group. At 12 months scores had levelled out and both groups demonstrated diminishing symptoms.

## **CHAPTER NINE: DISCUSSION OF SUBGROUP ANALYSIS**

#### 9:1 Interval variables

The initial data analysis demonstrates that a number of variables allow distinction to be drawn among these surviving ICU patients, with regard to psychological recovery. Commencing with the interval data, the age of the patient appears to allow a degree of discrimination. Overall psychological function as assessed by the GHQ28 appeared to be worse, self-esteem lowest and symptoms of post traumatic stress greatest in the younger patients, that is those from the 18 to 30 years group. Older patients initially reported some psychological dysfunction at six weeks, but this had reduced at six and twelve months, indeed by the end of the year those in the oldest age group (57 to 69 years) had the lowest GHQ scores, and the lowest SES scores, indicating best psychological function and best self esteem, of all the patients.

The GHQ subscales offered further discrimination, with patients from the youngest age group (18 to 30 years) recording highest scores on the anxiety and depression subscales. A statistically significant difference was found between the youngest age group (18 to30 years) and the oldest age group (57 to 69 years) for scores on the GHQ depression subscale at six months. The only area in which older patients fared worst was in social function, as measured by the GHQ subscale: at six weeks and six months their scores reflected poorer perceived social function, although statistical significance was not attained.

Self esteem scores appeared to keep pace with GHQ28 scores, in that poor psychological function was accompanied by low self esteem. Post traumatic stress symptoms, as measured by the IOES, also appeared more prevalent in the youngest age group, and least apparent in the older age groups.

The discrepancy between age groups may be explained by poorer physical condition at discharge, equally it may be a function of expectation. Older people may not welcome severe illness but it is perhaps more of a surprise or insult to the young to be afflicted with a life threatening illness. Some of the differences may have arisen as a result of changed expectations in older individuals, or because of the different "assumptive worlds" inhabited by the old and the young. The varied scores produced by old and young survivors may be a product of different ways of coping. The work of theorists such as Janoff Bulman (1989), and Wortman (1992), who describe PTSD in relation to shattered mental constructs, may cast some light on the findings here, and this will be examined in more depth in the final discussion section. The age range of patients admitted to the ICU is considerable, and the consistent pattern seen, along with the statistically significant result found via the GHQ subscale in the younger age group, meant that age was considered an important variable to include in the regression analysis.

Length of stay in the ICU produced a somewhat unexpected finding, which was that patients who stayed longest in the unit (9 to15 days), reported better psychological function and self esteem than the shorter stay patients (2 to 8days). At twelve months psychological function, as measured by the GHQ, was significantly worse in the shorter stay group; also at both six and twelve months self esteem was significantly worse in this group.

Since length of stay is related to degree of need for intensive care, and hence to degree of sickness, the reverse might be expected: that is, worse function in those patients staying the longest. One possible explanation for the finding is that the sicker, longer stay patient may in fact receive greater input carewise from both staff and relatives, promoting a sense of wellbeing and consequent self worth. It is possible too, particularly in the current National Health Service climate, that those who were discharged from ICU after a short stay were not entirely well enough to leave and thus started their recovery at something of a disadvantage.

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Conversely, post traumatic stress symptoms, as measured by the IOES, were fewer at six weeks in the shorter stay group. One possible explanation for the difference may be the longer period of treatment in the longer stayers, during which they may have spent some time at least semi-conscious of events. This is however only speculation; IOES scores showed a general levelling at six months and by twelve months very little difference was apparent.

In the light of the findings regarding psychological function and self esteem, Length of stay in ICU was also seen as an important variable for inclusion in the regression analysis.

In relation to length of stay in hospital overall a somewhat similar pattern emerged, with long stayers reporting better wellbeing and higher self esteem - though as noted in the results section, the long staying groups comprised small numbers. Post traumatic stress symptoms were greater at six week follow up in the longer stay patients; however the scores levelled out over the year and this difference was not noticeable by the twelve month follow up. Overall this variable, "length of stay in hospital", added very little information to the findings.

Admission severity scores produced somewhat unexpected results when subgroup analysis was carried out. The patients who had been sickest on admission, as measured by the first day APACHE score, reported better psychological function across the entire follow up period than those who were least sick on admission. A statistically significant difference in psychological function, as measured by the GHQ, was found at twelve months between Groups 1 and 2, the patients with APACHE scores at the lower end of the scale, and Group 4, patients with the highest APACHE scores. The indication then was that those who were sickest on admission reported better function at the end of the follow-up period. This links too with the finding described above, where those staying longer on the ICU reported better psychological function by way of the GHQ28 scores, as the more physiologically deranged the patient (and the higher the APACHE score) the longer the stay is likely to be in the ICU.

Self esteem scores matched this pattern, in that the patients who were most severely ill on admission were those who enjoyed the best self esteem over the recovery period. This difference in self esteem levels was found to be statistically significant at all three follow up points, with difference detected on all three occasions between Group 1 (lowest APACHE scores, 1-10) and Group 3 (second highest APACHE scores, 21-30).

Again this finding could possibly be connected to the immense care and input received by the sicker patients - both from health professionals and family or friends - having some bolstering effect emotionally. One other possibility is different perceptions in those who have survived very severe, life threatening illness. It could be that wellbeing, and self esteem, are more likely to be perceived as good in those who have "cheated death" and are grateful to have survived the experience.

Post traumatic stress symptoms were greatest in the sickest patients initially, lowest in those who were in best condition on admission, but this pattern had reversed by twelve months such that symptoms had abated in the sickest patients and were more prevalent in the groups which were least sick on admission. Though tenuous, there may be a link with the generally worse psychological function, and worse self esteem these groups were reporting by the end of the follow up period.

Overall then, the best one year outcome, psychologically speaking, was apparent in the patients who had highest APACHE scores and were sickest on admission to the ICU, with a statistically significant difference in GHQ scores at 12 months, and in SES scores at all three follow up points. These findings supported the inclusion of admission severity in the regression analysis, and examination of findings related to this variable are continued in the final discussion section.

#### 9:2 Ordinal variables

The data dealing with recall of the ICU experience generated another relatively unexpected finding: that the most post-traumatic symptoms occurred in those who claimed to have no recall of the ICU experience, more so than in the groups with high, or vague recall. At six weeks, IOES scores were greatest in the "no recall" group, indicating the most by way of PTSD symptoms, and IOES scores were lowest in the "vague" recall group indicating fewest symptoms in these patients. The "no recall" group also had the highest IOES scores at 6 months. This result is of interest as it indicates symptoms of post traumatic stress even in patients who profess to have no recall for the experience. The lowest IOES scores were the patients with "vague recall". From the results of the initial analysis it appeared that patients with only "vague recall" emerged from the ICU experience with the fewest post traumatic stress symptoms.

It would seem then that even complete lack of recall for the ICU experience may be linked with PTSD symptoms in the aftermath of critical illness. Vivid memories of procedures and treatment in the ICU are disturbing enough for those who can recall the experiences; on the other hand amnesia for the event may be even more threatening. It is quite possible that patients may be regaled with detail from relatives or others as to the goings on while they were on ICU in a seriously ill condition. Even if they are spared this, many may be aware they have had a brush with death. The finding of symptoms in those claiming absence of recall raises questions about post-traumatic stress, since these patients were reporting both avoidant behaviour - plausible enough - and intrusive thoughts. One possible mechanism for PTSD symptoms in patients who had claimed amnesia for the event was that the original questions about recall of ICU were put to the patients at the time of recruitment to the study. This was inevitably at an early stage after discharge from ICU when indeed the patients could not recall anything of the events. This may have been as a result of the drugs administered, or there may be a more complex explanation which centres on different memory forms. Squire (1992) has described two forms. First, <u>implicit</u> memory - particularly information relating to skills, habits or classical conditioning - which is found in the areas of the brain where initial encoding took place, such as the motor and sensory cortex, and the basal ganglia. Second there is <u>explicit</u> memory, which requires conscious awareness for an event to be processed, and is mediated via the hippocampus prior to consolidation in the cortex.

Siegel (1997) has looked at PTSD in the context of different forms of memory, and his theories include a point of particular relevance here - that is, that traumatic events are encoded in a different manner to other events and that in a traumatic situation the conscious attention required for the processing of explicit memory is lacking, as a result of emotional flooding during the trauma and focusing of attention away from events. It is thought too that the processing of traumatic events or emotional memories is routed via the amygdala, which may encode and store sensory data without hippocampal involvement (Davis 1992, Cahill et al. 1994). Further, as seen in Chapter 4, it has been proposed that the glucocorticoids released in extreme stress reduce hippocampal functioning, interrupting memory formation (Sapolsky et al. 1990, Cahill et al. 1994, Hagh-Shenas at al. 1999). Siegel (1997) puts forward a very feasible collection of reasons - excessive stress hormones, emotional overload and diverted attention - that processing of explicit memory should be hindered, yet processing of implicit memory is not. The result is that intact implicit memory, including hyperarousal and somatic symptoms, can occur in conjunction with impaired explicit memory - amnesia for the events. This explanation in part fits the picture presented by the results of this study where patients who said initially that they had no recall of the ICU experience nevertheless reported symptoms of PTSD. What is interesting - or perhaps disappointing - is the lack of differentiation made by the intrusive: avoidant subscales of the IOES. One might expect these "no recall" patients to be complaining of avoidant symptoms more than intrusive symptoms. Nevertheless the results of the recall subgroup were of great interest, and this aspect is raised again in the final discussion section.

Communication was included as a subgrouping variable, with patients answering the one question about communication which centred on their ability to make themselves understood. This was admittedly a crude measure, and communication was recorded as "good" or "poor" from what the patient said about their time in the ICU. What emerged from the analysis of the GHQ scores was that the "good communication" group reported poorer psychological function than the "poor communication" group. This difference was especially marked at 6 week follow up, where statistical significance was attained. Self esteem was also lower in the "good" communication group. PTSD symptoms in the "good" communication group actually got worse.

The perception of good communication by an ICU patient suggests of course that the patient spent at least some of the time awake and alert enough to experience some kind of communication with those around the bedside. The measurement of perceived communication within this study was admittedly one dimensional, though of course it was carried out as one of many measurements of the ICU experience.

The findings from the "communication" subgroup are not what one might expect given the emphasis traditionally laid on the promotion of "good" communication in ICU - that is that communication which is perceived as good is beneficial to the patient's psychological state. (Ashworth 1984, Pennock et al. 1994, Porter 1995). It may be that the level of awareness which allows "good" communication, goes hand in hand with cognisance of the activity and experiences within ICU, with resultant psychological problems. What the finding does contradict is the previously discussed finding of more PTSD symptoms in the "no recall" group - though for the recall subgroup the major differences detected were for IOES scores, and not particularly for the GHQ , which seemed to be the differentiating scale in the communication subgroups. Given the significant difference found at 6 weeks and also the unexpected nature of this finding, communication was included in the regression analysis.

The findings relating to social support bear out common observations of greater wellbeing in those who perceive a reasonable level of support. Those who lived alone with minimal support - admittedly a very small group of only 2 patients - reported a deterioration of function as measured by the GHQ over the entire twelve months follow up period. Those who lived alone but with next of kin also nearby - 9 patients (which had become 8 by the end of the year) reported a worsening of function over the follow up period, while those who had best support, living with next of kin, had high GHQ scores at 6 weeks but a very recognisable improvement over the follow up year. Self esteem patterns matched those of the GHQ, indicating a fall in self esteem accompanying a rise in psychological dysfunction.

Post traumatic stress symptoms too were worse in the small "minimal support" group, and were greater at twelve months than they had been at six. In the larger groups who perceived moderate or optimum social support, post traumatic stress symptoms abated over the follow up period. These findings lend some support to the notion that social support can have a positive or beneficial effect on those experiencing stress. Though concepts of social support vary, Bartlett (1998) suggests two broad areas - structural aspects which include social role and membership of social groups and networks, and *functional* aspects such as intimacy, attention and sense of worth. Stressful events rarely occur in a social vacuum, and the perception of support, or lack of it, may be an influencing variable. The buffer hypothesis suggests that perceived support may reduce the impact of stressful life events (Cohen & Wills 1985) and indeed may influence an individual's level of physical health (Wallston et al. 1983). It is though important to note that the research findings on social support and stress are not all consistent with the notion that support has a beneficial mediating effect (Snyder & Ford 1987). The measure of social support here was purely structural - that is it centred upon who was available in the patient's immediate vicinity, and nothing was measured of functional aspects of support. Again this was an effort to keep the large number of variables manageable, but the somewhat one dimensional nature of the measure is acknowledged.

Nevertheless the findings here do demonstrate some relationship between perceived support and psychological recovery after intensive care.

Subgrouping for sleep produced minimal difference by way of GHQ28 or SES scores, though psychological function and self esteem appeared slightly worse in the group reporting "poor" sleep, in particular at the twelve month follow-up. The IOES offered some distinction in relation to this variable however, with those who reported "poor" sleep having higher IOES scores, indicating more PTSD symptoms, over the follow up period. For the other group - " slept reasonably or well" - post traumatic stress symptoms tended to diminish to a low level by the end of the first year. No statistically significant between group differences were seen for the total IOES scores, though one significant finding between groups arose on the "intrusive" subscale of the IOES at twelve months.

As seen in Chapter Four, research into the neuropsychology of PTSD has demonstrated deranged biology in PTSD sufferers; in particular McGough (1992) has described how increased cortisol releasing factor, in a post traumatic stress state, results in enhanced neurotransmission in the locus coeruleus leading to vivid dreaming and disturbed sleep. It may be that some feedback mechanism is set up after extraordinary trauma is experienced, contributing to poor sleep and PTSD symptoms like odd REM sleep and graphic dreams. Again these possibilities feature in the final discussion chapter. The findings for this subgrouping were not particularly conclusive, notwithstanding the one between group difference found on the IOES subscale.

#### 9:3 Categorical variables

Moving to the categorical variables, first occupational classification, here a pattern was quite difficult to discern, and no statistically significant findings emerged. Semi-skilled manual workers and the two students had highest GHQ scores, and clerical or minor supervisory

workers lowest. GHQ scores in professionals increased over the follow up period indicating a worsening of psychological function in this group. Self esteem scores at 6 months were highest in the students indicating a lower sense of self esteem. This was a very small subgroup whose members were also some of the youngest participants in the research. It has been seen already from these initial results that younger age groups are linked with lower wellbeing, self esteem and greater post traumatic stress; given the absence of any strong pattern within the occupational class subgroups, and the small number in the subgroup, it is possible that this finding is spurious and is in fact more likely to be a function of the students' young age. However there is a possibility that the finding had some validity, since the students in question all lost time on their courses and at least one dropped back a year as a result of the illness. The six month period may have been the point at which this had an effect on the individuals' self image and consequently self esteem. They were - albeit temporarily no longer students, which put them outside the occupational role they were becoming accustomed to. It has been noted already that the Rosenberg Self Esteem scale was developed around adolescent subjects and that there may well be parallels between the fragility of self esteem endured during adolescence, and those experienced after critical illness (see Chapter Six). These particular patients were perhaps in double jeopardy - only just emerging from adolescence, and then assaulted by sudden critical illness necessitating ICU admission. In addition the physical effects of illness may still have been present in some degree. This combination of events could conceivably reduce the sense of self esteem, and satisfaction with self image, at least for a short while.

With regard to indication for admission, or illness groups, patients admitted as a result of trauma reported worst long term psychological function, as discerned by the GHQ28 scores, followed by the unplanned surgery group. The trauma group had highest GHQ scores across the follow up period. The scores on the GHQ depression subscale at 6 weeks showed statistically significant difference between the trauma group and the transplant surgery group; significant difference was also found at 6 months between the same two groups.

Initially respiratory disease and liver transplant patients had lowest GHQ scores indicating best psychological function. The transplant patients formed the largest group; their GHO scores increased very slightly at 6 months. The transplant patients' scores had not fallen by very much at the 12 month point indicating little change between 6 and 12 months. Self esteem in this group also diminished over the follow up period, though self esteem was worst overall throughout follow-up in the trauma group. The first year post transplant can be unpredictable and it is perhaps possible that the initial relief and euphoria engendered by receiving a new organ could be tempered as time passes. The transplant operation may come after an anxious period of waiting and as such may be seen as the answer to many problems. Yet transplant patients have to endure a great deal in the recovery period (Wainwright 1997). Metabolic readjustment and immunosuppressive therapy can both lead to behavioural disturbances; in addition these patients must contend with the fear that the new organ may be rejected or that sepsis will occur. On a practical note the intensive follow up requires frequent trips to hospital which for those at the furthest edges of the region means a lot of travelling and expense. Such a combination of factors may explain in part the pattern of psychological wellbeing reported by this subgroup.

PTSD symptoms were markedly higher in the trauma group, and a statistically significant difference was found at 6 weeks between the trauma group and the planned surgery group. As mentioned previously there is a possibility that the original trauma may be entangled with any trauma from the ICU experience, despite attempts to reduce the likelihood of this. The trauma group was a small one, yet the consistently higher scores on all three scales, and the statistically significant findings at 6 weeks and 6 months were clearly of interest, and indication for admission was therefore included as a variable of interest in the regression analysis.

Some further discrimination was made in relation to the patient's mode of admission. Worst psychological function as measured by the GHQ was apparent in those patients who were

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admitted to the ICU while still conscious. The group admitted unplanned from theatre - which generally implies some unforeseen complication during surgery necessitating unplanned admission - seemed to have least by way of psychological dysfunction over the follow-up period. It was clear from the SES scores that self esteem matched these findings, with the "conscious" group displaying lowest self esteem and the "unplanned from OT" group best self esteem across the twelve months.

Most symptoms of PTSD were also evident in the "conscious" group at six weeks, and fewest in the "elective" group - that is, patients whose ICU admission had been prearranged, as a necessary adjunct to elective surgery. Higher levels of symptoms persisted in the "conscious" group; by twelve months those displaying fewest symptoms were patients in the "unconscious" mode of admission group. A significant difference was detected between groups initially, but post hoc testing failed to confirm this. The "conscious" group was a very small one by the time follow-up was commenced and it was thought possible that this was a spurious finding. Nevertheless, the results suggested that arrival on the ICU in a conscious state may possibly be associated with poorer psychological function in the recovery period, from the GHQ, SES and IOES scores. This is not a surprising finding. Despite every effort on the part of the staff involved in the transfer - meaning both the receiving intensive care staff, and the staff of either the referring ward or the A&E department - conscious admission to the ICU with no planning or preparation has the potential to be a quite disturbing experience and it is no real surprise that it may predispose to unpleasant flashbacks or memories for this group regardless of sedation following admission.

Alternatively the findings may be explained by nature of the illness. Those coming straight from A&E or the ward may have had a rapid onset of critical illness, while those admitted electively were possibly more prepared for admission, not just psychologically by way of information about and orientation to the unit, but by attention to their physical status. Similarly, patients who come to ICU unplanned via the operating theatre are very often those

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in whom some complication has occurred during routine surgery. This does not diminish their status as critically ill and their need for intensive care, but it may mean that attention has been paid to aspects such as fluid and electrolyte balance, haematological status, or the need for antibiotic cover, in the hours immediately preceding ICU admission. In this way these two groups may possibly start off at some advantage, and this could be reflected in their better sense of wellbeing after discharge.

The lower level of PTSD symptoms in the elective admission group is also to be expected, given the psychological preparation which may accompany this mode of admission. These patients generally arrive after some planned major surgery and they will have been informed of the need for a period of intensive care. Of course the level of preparation offered on different wards will vary. Some patients are brought to see the ICU beforehand, others will receive information on the ward, and this was admittedly an uncontrolled factor in the study. One interesting additional finding was that this elective admission group reported little improvement in function via the GHQ at twelve months. As described, the group had reasonably low scores initially, but it seems too that their sense of psychological wellbeing did not get better with time.

In analysis via sex groups, men and women showed different recovery patterns though none of these differences reached statistical significance. Psychological function as measured by the GHQ, and self esteem, were initially better in men and worse in women, but this situation was reversed by the end of the twelve months when dysfunction overall - by way of somatic symptoms as well as anxiety, social dysfunction and depressive symptoms, was more apparent in the men. Stewart & Salt (1981) have suggested that in relation to stress resulting from adjustment to change, for the same amount of change women are more likely to become depressed, men more likely to become ill. The question of illness brought about by stress is of course confounded in this study because of the patients' initial critical illness. However it is interesting to note that women in this study do not fit the picture of susceptibility to

depressive symptoms, indeed they display an improvement via the GHQ28 scale over the 12 month follow up period in relation to men.

In contrast post traumatic stress symptoms were reported in greater amount by men initially, but their scores diminished over the follow up period. Women on the other hand showed no improvement in post traumatic stress symptoms from six weeks to six months, though by 12 months their symptoms too were fading.

Presence of relatives during the ICU stay produced no startling discrimination although it was seen that those who had had relatives present during their stay enjoyed better wellbeing as measured by GHQ scores, higher self esteem overall, and least by way of PTSD symptoms. This again may have links with social support and its buffering effect as discussed previously. In particular the presence of relatives may fulfil some of the functional aspects of social support (Bartlett 1998), where the patient may possibly sense the presence and closeness of the resident relative with a consequent positive start to the recovery process. Frequent visiting by spouses has been associated with more rapid recovery after surgery (Kulik & Mahler 1989) though post operative visiting cannot perhaps be fully compared with the vigil often kept by relatives on the ICU, who understandably suffer from stress and exhaustion themselves (Molter 1979, Coulter 1989, Wilkinson 1995).

In relation to muscle relaxants, or paralysing drugs, during ventilation, one finding of interest emerged, though the large discrepancy in group size must be considered too. Psychological function and self esteem appeared to be better in the group which <u>did</u> receive relaxants during ventilation; the IOES scores were also noticeably lower in the "received " group indicating fewer post traumatic stress symptoms. A statistically significant difference in total IOES scores at 12 months was found. Though this may have been an isolated result it is worthy of comment in that it contrasts strongly with findings of post traumatic stress symptoms in patients who have undergone general anaesthesia for surgical procedures. Here the patients at risk of traumatic memories are those who were paralysed by muscle relaxants, in cases where anaesthesia and analgesia have been inadequate yet the patient has endured the horror of being unable to alert anyone (Miller 1987). These two clinical indications for muscle relaxants - during general anaesthesia to facilitate surgery, and as an adjunct to ventilation for respiratory failure - constitute very different circumstances which relate to different types of patient, and therefore any meaning which can be inferred from this study's results is limited. The finding was striking and the results suggested that this was a variable which should be examined further by way of regression.

In the groups separated according to cancer as a pre-existing condition, little difference in psychological function or self esteem was noted. SES scores were slightly higher in the cancer patients at 6 weeks and 6 months, an indication of lower self esteem. However the non-cancer patients were found to have higher IOES scores than cancer patients, indicating more post traumatic stress symptoms in those with no cancer. This difference reached statistical significance at six weeks and six months and cancer as a variable was included in the regression analysis.

It is not uncommon for patients receiving treatment for cancer to find themselves admitted to the ICU either following radical surgery - in which case admission is often planned - or for supportive care during complications of chemotherapy. Cytotoxic therapy for cancer is a double edged sword, and while aggressive drugs may attack haematological malignancies or tumour growth, their effect is sometimes to jeopardise other systems, necessitating temporary respiratory or systemic support. Those patients who have been through the initial distress of cancer diagnosis and therapy may to a degree be inured to the experience of exhaustive treatment and invasive procedures. Hence the finding, in this sample of patients anyway, of significantly less post traumatic stress, related to the ICU experience, reported by cancer sufferers over the first six months. It could be surmised that invasive procedures and the trappings of ICU may be considerably more stressful to those who have had no similar

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experience. These points are raised in the final discussion chapter in relation to the question of assumptive worlds and previous experiences.

Coincidental life events were recorded along with the final follow up test responses, to ensure validity of the study, that is to be as certain as possible that participants were reporting psychological wellbeing in relation to the ICU experience itself rather than have the overall scores tainted by the stress of life events coinciding with the follow up period. There was little difference evident by way of the GHQ scores though psychological function was slightly worse in the group which did report coincidental life events. This group also had slightly higher SES scores indicating lower self esteem. This difference did not reach statistical significance but is of course of note, and is in keeping with notions of a link between stressful life events and sense of self esteem (Abramson et al. 1978) and between life events, illness and self esteem (Brown & Harris 1989). It may be that for some patients the occurrence of stressful life events superimposed upon the recovery period resulted in a greater sense of psychological dysfunction, and a comparatively low self esteem as measured by the Rosenberg scale. IOES scores were similar in both groups at 6 weeks, higher at 6 months in the group which did report events, and diminishing in both groups by 12 months. This may be spurious, it may be that the stressful life events coincided with the 6 month follow up point for the patients - unfortunately the precise timing of the life event was not recorded, thus interpretation of these particular results is somewhat limited.

The analysis conducted at this stage satisfied objectives 1, 2, and in part 3 and 4 of the study, as described in Chapter One. These were to assess psychological wellbeing at intervals following discharge, to identify ICU related variables influencing recovery, to examine the relationship between these variables and the assessment outcomes, and to identify risk factors.

The picture created thus far of these ICU survivors was one of differing recovery patterns for different patient groups, underpinned by an apparent association with a variety of factors.

These included demographic variables like age, clinical variables such as admission mode, illness type or presence of cancer, and less tangible aspects such as recall for events, perceived communication, and social support. Some of these variables emerged as clearly more significant than others.

At this stage it was useful to pause and consider the emerging picture of recovery, and to ascertain which of the measured variables might usefully be included in the next step of the analysis. Some explanatory mechanisms in relation to psychological outcome were beginning to emerge. Which features are related to poor outcome, and which to better outcome? Table 9a below gives an indication across all the measured variables of good versus poor outcome.

# Table 9a: Features of all ICU variables related to best and worst outcome

OUTCOME	Worst	Best	
1.Age	Young (18-30years)	Older (>57years)	
2.Length of stay	Shorter (2-8days)	Longer(>9 days)	
3.Admission severity	Not severe	Severe	
4.Recall	No recall	Vague recall	
5.Communication	Good	Poor	
6.Social support	Minimal	High	
7.Sleep	Poor	Good	
8.Occupational class	Student, semiskilled manual	Clerical/minor supervisory	
9.Mode admission	Conscious	Unplanned	vi
OT,Unconscious			
10.Illness	Trauma	Metabolic/planned surgery	
11.Sex	Either	Either	
12.Relatives	Not resident	Resident	
13.Muscle relaxants	Not received	Received	
14.Cancer	No	Yes	
15.Coincidental life	Yes	No	
events			

However, as seen from the results of the initial analysis, a smaller number - seven variables in all - emerged from the initial analysis as particularly influential and of interest. These seven variables were :-

- Patient's age
- Length of stay in ICU
- Admission severity score
- Perceived communication
- Indication for admission
- Administration of muscle relaxants
- Presence of cancer as part of the original problem.

Some explanations have already been proposed within this initial discussion as to why these variables might allow differentiation in psychological recovery patterns, the concluding discussion will return to many of these points. The final stage of data analysis then was to take these variables which stood out, and submit them to a correlation and then regression analysis.

#### **CHAPTER TEN: REGRESSION ANALYSIS**

From the initial analysis several variables of interest became apparent. Objectives Three and Four of the study involved examination of the relationship between the ICU variables and the findings from the outcome assessment, then identification of factors which indicate risk and may predict outcome in relation to psychological wellbeing. Despite the relatively small scale of the study a number of significant variables were available for entry into further analysis. Those which emerged as significant differentiators in the subgroup analysis were examined to discern their effects on the outcome measures - that is the scores on the General Health Questionnaire, Self esteem scale and the Impact of Event scale.

#### 10:1 Correlation Analysis

As a first step towards identifying any predicting factors, correlation analysis was performed on the outcome variables (total scores for all three tests at 6 weeks, 6 months, 12 months) with the differentiating variables produced by the initial analysis. The test of choice was Kendall's tau since it is considered better at dealing with tied ranks (Bryman & Cramer 1994, Robson 1993) and the outcome data here contained a high proportion of tied ranks by the nature of the scoring systems (0,1,2,3) for the GHQ, SES and IOES.

The variables age, length of stay in ICU, admission severity, communication, illness, relaxants, and cancer were entered into a correlation analysis with General Health Questionnaire (GHQ28) scores, Self esteem scale (SES) scores and Impact of Event scale (IOES) scores at 6 weeks, 6 months and 12 months. The variables communication, illness, relaxants and cancer, which were non-interval in nature, were transformed by the creation of dummy variables to allow their entry into the analysis. This procedure allows the inclusion of

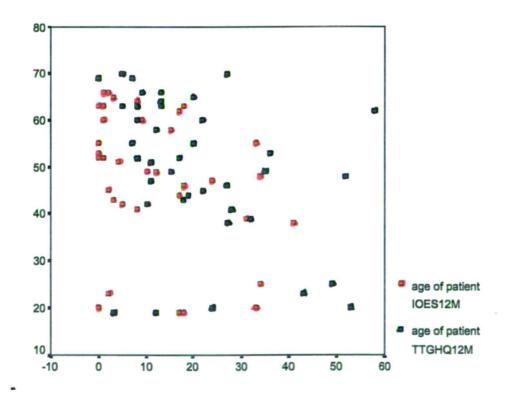
non-interval variables in a correlation analysis; the resulting coefficients can then be interpreted in the same way as those based on interval variables (Bryman & Cramer 1994).

#### 10.2 Findings, correlation analysis

Results from the correlation matrix confirm the findings from the analysis of subgroups:-

Age of patient correlates negatively with total GHQ28 scores at twelve months (r = -.24, 2-tailed p< 0.05), and negatively with IOES scores at six weeks (r = -.28, 2-tailed p< 0.01), at six months (r = -.23, 2 tailed p< 0.05) and at twelve months (r = -.29, 2 tailed p< 0.05). (See Figure 10:i)





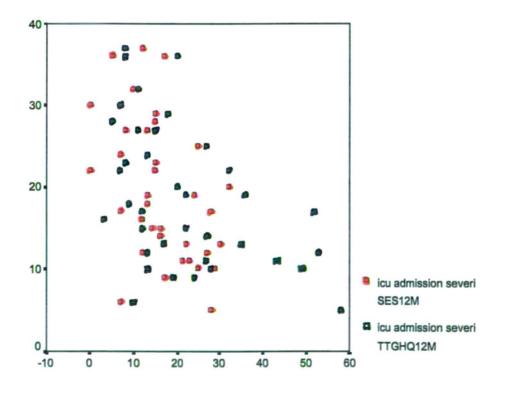
x axis = psychometric scores y axis = age in years

Length of stay in ICU correlates negatively with GHQ at 12 months (r = -.24, p<0.05), and positively with IOES at 6 weeks (r = .26, p<0.05).

Admission severity scores correlate negatively with total GHQ28 scores at twelve months (r = -.35, 2-tailed p < 0.01) and negatively with SES scores at six weeks (r = -.24, 2-tailed p < 0.05), at six months (r = -.33, 2-tailed p < 0.01) and at twelve months (r = -.33, 2-tailed p < 0.01).

(See Figure 10:ii)

## Figure 10:ii. Overlay scatter plot of admission severity scores with GHQ and SES scores at 12 months.



x axis = psychometric scores

y axis = admission severity (first day APACHE scores).

<u>Good communication correlates positively with total GHQ28 scores at six weeks</u> (r = .27, 2-tailed p < 0.05).

Trauma as an indication for admission correlates positively with IOES scores at six weeks (r = .32, 2-tailed p < 0.05)

Receiving of muscle relaxants correlates negatively with IOES scores at twelve months (r = -.28, 2-tailed p < 0.05)

Presence of cancer correlates negatively with IOES scores at six weeks (r = -.29, 2-tailed p < 0.05)

	Age	StayICU	Severity	Comm <sup>n</sup>	Trauma	Relaxant	Cancer
GHQ6wks	ns	ns	ns	.267*	ns	ns	ns
GHQ6ms	ns	ns	ns	ns	ns	ns	ns
GHQ12ms	239*	243*	345**	ns	ns	ns	ns
<b>SES6wks</b>	ns	ns	244*	ns	ns	ns	ns
SES6ms	ns	ns	325**	ns	ns	ns	ns
SES12ms	ns	ns	332**	ns	ns	ns	ns
IOES6wks	284**	.260*	ns	ns	.318*	ns	290*
IOES6ms	229*	ns	ns	ns	ns	ns	ns
IOES12m	297*	ns	ns	ns	ns	280*	ns
s							

Table 10a below displays the significant results emerging from the correlation analysis. Table 10a: Kendall's Tau correlations between ICU variables and outcome scores

GHQ6wks = GHQ28 score at six weeks

GHQ6ms = GHQ28 score at six months

GHQ12ms = GHQ28 score at twelve months

SES6wks = Self esteem score at six weeks

SES6ms = Self esteem score at six months

SES12ms = Self esteem score at twelve months

IOES6wks = Impact of Event score at six weeks

IOES6ms = Impact of Event score at six months

IOES12ms = Impact of Event score at twelve months

 $Comm^n = Communication$ 

- \* = statistical significance, 2-tailed p < 0.05
- **\*\*** = statistical significance, 2-tailed p < 0.01

Correlations among the total scores for the outcome measures themselves were also examined in order to see the existing inter-relationships. The Spearman correlation coefficients were recorded, and a high degree of association was apparent as can be seen in the table in Appendix XIV. In particular, GHQ scores and SES scores were correlated at all three followup points at a statistical significance level of p<0.01; GHQ and IOES scores at 6 and 12 months were also strongly associated at p<0.01. SES scores also correlated with IOES scores at all three follow-up points at a significance level of p<0.01. Overall there was strong indication of a relationship among the aspects of psychological function being measured by the three tests, namely psychological wellbeing, self esteem and symptoms of PTSD.

#### 10:3 Regression Analysis

Regression analysis was undertaken with the ICU variables identified as significant - age, length of stay in ICU, admission severity, communication, illness, relaxants and cancer - as independent variables. This was an attempt to complete objective Four - identification of factors which indicate risk and may allow prediction of outcome. The rationale for undertaking a regression analysis derives from the discussions following the initial analysis. There are plausible explanations as to how any of these variables might have predictive value in relation to the outcome scores - clearly some are more tenuously linked than others but none is too remote from the area of interest - that is, psychological wellbeing.

Up to this stage of the analysis non-parametric tests had been used. Although there is an argument for treating data such as those generated by the assessments as interval, and thus using parametric tests (Bryman & Cramer 1994), some of the sample sizes were ill matched and so non parametric testing was used, to ensure that the initial identification of important variables was as rigorous as possible. Using non-parametric testing in the first and second stages of the analysis meant that those results which were statistically significant had emerged

via the most difficult route - it would perhaps have been possible to see even more by way of statistical significance had parametric testing been used for the subgroup analysis.

However having reached this stage it was necessary to change the approach to try and answer the last question - do any of these variables have predictive property? Regression, and multiple regression may primarily be considered techniques applied to parametric data (Anthony 1999), although parametric tests are routinely applied to many psychological and sociological variables, as has been noted by Bryman & Cramer (1994) and Norusis (1990).

The variables of interest which emerged from the subgroup analysis were of mixed levels of measurement, continuous and categorical; further it was possible to dichotomise the outcome variables by way of the categories described in Chapter Eight (see Tables 8g, 8h, 8i) such that patients may have GHQ scores above or below the threshold for "caseness" (Goldberg & Williams 1991), may have self esteem scores in excess of 50% of the maximum possible score, or may have PTSD symptoms classified as a "high" level (Horowitz et al. 1981).

The technique of logistic regression will predict the presence or absence of a dichotomised outcome, based on the values of a set of predictor variables. As a multivariate technique it is less reliant on distributional assumptions than methods such as discriminant analysis (Norusis 1990), and is less likely to violate parametric assumptions (Tabachnick & Fidell 1989). The logistic regression approach can be applied where independent variables are a mix of continuous and categorical, and it has been described as a useful tool in health care research for identifying factors which may determine particular outcomes or situations (Field 2000).

The dependent variables were therefore dichotomised as explained below, in order to submit them to the logistic regression procedure.

#### General Health Questionnaire 28 item version (GHQ28)

Threshold scores for the GHQ28 have been discussed in Chapter Eight in calculation of the percentage of patients reporting psychological dysfunction. The threshold score indicates the number of symptoms, as recorded by the GHQ28, at which the probability of diagnosing psychiatric "caseness" exceeds 0.5. The recommended threshold score in this group, using simple Likert scoring, has been taken as 39/40 (Goldberg & Williams 1991). A total score of 39 was therefore taken as the cut-off point for the GHQ28, for all three follow-up points, thus logistic regression could be used to predict the occurrence, or non-occurrence of a degree of dysfunction which might, if so required, allow detection of "caseness" in test respondents.

#### Rosenberg Self Esteem Scale (SES)

Little has been found in relation to cut-off points for the Rosenberg scale. As discussed in Chapter Eight, using simple Likert scoring the maximum possible score here was 51. In Chapter Eight the calculation of the percentage of patients reporting low self esteem was made using 25 - a halfway point - as a cut-off. This offers a division into those with scores on the lower half and scores on the higher half of the scale, remembering that high scores reflect low self esteem, and that the best self esteem would actually be indicated by a score of 0. Thus even a score of 25 indicates a score which is 50% of the maximum possible. Therefore an SES score greater than 25 was used as the cut-off for the Rosenberg scale, allowing prediction of occurrence of low self esteem in this group of patients.

#### Impact of Event Scale (IOES)

As discussed in Chapter Eight threshold scores distinguishing between levels of PTSD have been described by the test's authors, with scores above 9 indicating a global indication of PTSD which warrants further evaluation, and scores above 19 indicating PTSD symptoms which may indicate pathology and certainly merit concern (Horowitz et al. 1981). A score of 19 or over was used as the cut-off point for the IOES, allowing prediction of a level of PTSD symptoms which warrants attention.

The correlation matrix for the significant ICU variables with all the outcome scores has been discussed above. It is also important to examine relationships among the prospective independent variables in a regression analysis, since multicollinearity may exist with consequent unreliability of regression coefficients (Bryman & Cramer 1994). The Kendall's Tau correlation analysis demonstrated one instance of a statistically significant relationship between the independent variables, which was the correlation between age and trauma where r = -.27, p < 0.01. This suggests a negative correlation with trauma featuring more frequently in younger, and less in older patients - an expected finding. However, no correlation coefficient exceeds the threshold of 0.8 ( the limit suggested by Bryman & Cramer 1994) and it appears that no great degree of multicollinearity exists to weaken the regression analysis, although as pointed out by Bryman & Cramer (1994) the independent variables in a multiple regression will generally be related to each other in some way.

A forward stepwise method was selected. Field (2000) suggests that stepwise methods may be of use in fields where previous research is scarce, as in this study, where predicting factors for ICU outcome have not fully been identified. The method initially uses only a constant in the regression equation, then adds predictor variables one at a time, with the criterion for addition being the value of the "score" statistic; that is the variable with the most significant score statistic is added to the model, followed by any other variables until a cut-off point is reached. A summary statistic, the log-likelihood statistic (or within SPSS, the value of  $-2 \times \log \log \log 1$  is calculated with and without inclusion of any predicting variables. The reduction in value of -2LL indicates how much better the model predicts the outcome variable once the predictor variable has been added. The Wald statistic for each

predicting variable is then examined, in order to see if any can be removed without significantly affecting the fit of the model to the data (Field 2000).

A classification table indicates how successfully the model will predict group membership, quoting the percentage of cases correctly classified with the inclusion of the predictor. The SPSS analysis also calculates a value, ExpB, which is interpreted as the change in odds, or likelihood of group membership, if the predicting variable is present. A value of ExpB >1 indicates that as the predictor variable increases, the odds of membership of the designated outcome group increase; a value of ExpB <1 indicates that as the predictor variable increases, the odds of membership of the outcome group decrease.

#### 10:4 Findings, regression analysis.

Separate regressions were performed for each of the follow-up points, representing predictive relationships at the three different follow-up points: six weeks, six months and twelve months.

Table 10b summarises the results of the separate analyses.

#### Six weeks outcome scores.

#### <u>GHQ</u>

Trauma, as an indication for admission, reduces -2 LL from 35.05 to 19.01. The value of expB is 9.0 indicating that the odds of membership of the group with GHQ scores >39, (the occurrence of psychological dysfunction which could constitute "caseness"), increase in the

presence of the illness variable trauma. Overall classification accuracy of the model is 90.9%.

#### <u>SES</u>

None of the variables emerged as a significant predictor of membership of the low self esteem group.

#### <u>IOES</u>

Cancer as a pre-existing condition reduces -2 LL from 58.70 to 54.67. ExpB is 0.26, indicating that presence of the cancer as a pre-existing condition decreases the odds of membership of the group with IOES scores >19 (a "high" level of PTSD). Overall classification accuracy of the model is 68.2%.

#### Six months outcome scores.

#### <u>GHQ</u>

Trauma reduces -2LL from 34.14 to 23.79. ExpB is 1.04, indicating that the odds of membership of the group with GHQ score >39 are very slightly increased by presence of trauma. Overall classification accuracy of the model is 90.2%.

#### <u>SES</u>

None of the variables emerged as a significant predictor of membership of the low self esteem group.

#### <u>IOES</u>

None of the variables emerged as a significant predictor of membership of the high IOES scores group.

#### **Twelve months**

#### <u>GHQ</u>

Admission severity score reduces -2LL from 29.31 to 22.78. ExpB is 0.8, indicating that as the admission severity score increases, the odds of membership of the group with GHQ scores >39 decreases. Overall classification accuracy of the model is 86.5%.

#### <u>SES</u>

Admission severity score reduces -2LL from 41.05 to 35.80. ExpB is 0.88, indicating that as the admission severity score increases, the odds of membership of the "low" self esteem group (SES scores >25) decreases. Overall classification accuracy of the model is 75.7%.

#### <u>IOES</u>

Age reduces -2LL from 50.62 to 45.58. ExpB is 0.95, indicating that as age increases, the odds of membership of the group with IOES scores >19 (a "high" level of PTSD) very slightly decrease. Overall classification accuracy of the model is 59.5%.

follow-up point.
t each
equations a
included in
Variables
Table 10b:

Scorevariablein -2LL <sup>1</sup> Coefficient $\&$ -2LL <sup>2</sup> $\&$ -2LL <sup>2</sup> $9.00$ $GHQ6weeks$ Illness(trauma) $16.04$ $2.20$ $9.00$ $GHQ6month$ Illness(trauma) $10.35$ $2.02$ $1.044$ $GHQ1 year$ Severity $6.53$ $-0.22$ $0.80$ $SES6weeks$ none $-0.22$ $0.80$ SES6weeksnone $-0.22$ $0.80$ SES6monthnone $-0.22$ $0.80$ SES 1 yearSeverity $5.25$ $-0.12$ $0.88$ IOES6weeksCancer $4.03$ $-1.36$ $0.26$	Predicting Difference B	ExpB	Wald	Model		% Correct
& -2LL <sup>2</sup> Illness(trauma)       16.04       2.20         Illness(trauma)       10.35       2.02         Severity       6.53       -0.22         none       -0.22       -0.22         none       -0.22       -0.22         Severity       5.25       -0.12         Cancer       4.03       -1.36         none       -1.36	in -2LL <sup>1</sup>		statistic	Chi Square	Significance	Classification
Illness(trauma)       16.04       2.20         Illness(trauma)       10.35       2.02         Severity       6.53       -0.22         none       -0.22       -0.22         none       -0.22       -0.22         severity       5.25       -0.12         Cancer       4.03       -1.36         none       -0.12       -0.12	& -2LL <sup>2</sup> *					
Illness(trauma)       10.35       2.02         Severity       6.53       -0.22         none       -0.22         none       -0.22         none       -0.22         Severity       5.25       -0.12         Cancer       4.03       -1.36         none       -0.12       -0.12	16.04	9.00	3.34	16.05	0.01	90.9
Severity       6.53       -0.22         none       -0.22       -0.12         none       -0.12       -0.12         Severity       5.25       -0.12         Cancer       4.03       -1.36         none       -1.36       -1.36	10.35	1.044	6.48	10.34	0.047	90.2
nonenonenone-0.12Severity5.25Severity1.36Cancer4.03none-1.36	6.53	0.80	3.55	6.52	0.01	86.5
none         -0.12           Severity         5.25         -0.12           Cancer         4.03         -1.36           n         none         -1.36						
Severity         5.25         -0.12           is         Cancer         4.03         -1.36           th         none         -1.36						
Cancer         4.03         -1.36           none	5.25	0.88	3.84	5.25	0.02	75.7
	4.03	0.26	3.86	4.03	0.045	68.2
IOES 1 year Age 5.04 -0.05 0.95	5.04	0.95	4.29	5.03	0.025	59.5

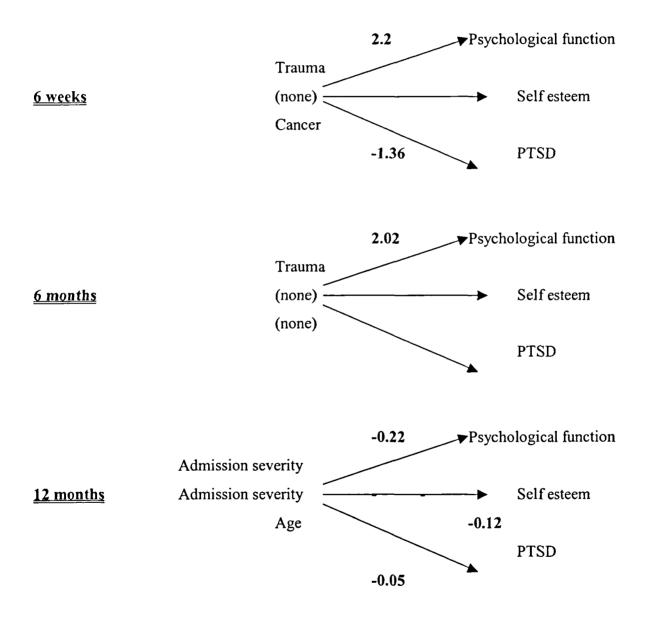
\*-2LL<sup>1</sup> = value of -2 log likelihood statistic before inclusion of predicting variable \*-2LL<sup>2</sup> = value of -2 log likelihood statistic after inclusion of predicting variable

#### **CHAPTER ELEVEN. DISCUSSION OF REGRESSION ANALYSIS**

The results of this analysis answered one of the final questions asked by the study: can predicting factors be identified in relation to good or bad psychological outcome after intensive care, for this sample of patients? Predicting variables were found for each stage of the follow-up. Trauma predicted higher GHQ scores and pre-existing cancer predicted lower IOES scores at six weeks; trauma also predicted higher GHQ scores at six months. At twelve months higher admission severity scores predicted lower GHQ and SES scores, and greater age predicted lower IOES scores.

However the values of the log-likelihood statistic, and the alteration in odds indicated by the ExpB values, suggest that only limited importance can be attached to these variables as explanatory factors of overall variation in outcome. Strongest of all the predicting variables, as indicated by the regression analysis results, was trauma as a predictor of GHQ scores above the threshold of 39. It is important, then, to be cautious in interpretation of these results, a caveat which has been applied throughout this exploratory research. Nevertheless, the correlation and the logistic regression analyses both lend support to the findings of the initial subgroup analysis, and add to them by indicating which of the ICU variables might have some predictive properties. Figure 11:i is the diagrammatic representation of a model indicating the predictors of psychological outcome after ICU as found by the study.

# Figure 11:i: Model for psychological outcome after ICU, as measured by the GHQ28 (psychological function), the Rosenberg Scale (self esteem) and the Impact of Event Scale (PTSD).



Numbers represent logistic regression B coefficients for predicting variables

The variables included in the regression are discussed below. Those which did not emerge as significant predictors - that is, length of stay in ICU, communication and use of muscle relaxants - are included here in order to offer a more complete discussion, though it is clear that in this study the null hypothesis must be accepted for these variables.

#### <u>11:1 Age</u>

In the correlation analysis, age was found to have a significant negative correlation with a number of outcome measures: with GHQ scores at final twelve month follow-up, and with IOES scores at all three follow-up points. Also, from the regression analysis, age emerged as a predicting factor, with a negative regression coefficient, for scores on the IOES at twelve months, suggesting that the younger patients may be more likely to suffer from post traumatic stress symptoms one year after discharge from the ICU.

Stress theory and PTSD theory both become relevant in explaining this differentiation whereby younger patients experience more problems than the older groups. From examination of the subgroup analysis it seems that the older the patient, the lower the reported scores on the GHQ, and the IOES, with low scores on the GHQ indicating better wellbeing, and low scores on the IOES indicating minimal symptoms of post-traumatic stress. In addition to this, the age appears to be a predicting factor, in a negative direction, of PTSD one year after discharge. These findings support and expand those of Ridley & Wallace (1990) who described decline in QOL as greater for younger survivors, and those of Tian & Miranda (1995) whose study demonstrated a significantly greater reduction in psychosocial wellbeing post-discharge in younger patients.

This distinction between older and younger survivors of intensive care may have several explanations. Explanatory factors may include fixed things such as the nature of the illness leading to ICU admission, or more fluid factors like individual expectations and demands in

relation to wellbeing. Analysis of the different age groups cross tabulated with illness type (see Chapter Eight, Table 8b) shows differences which may furnish some explanation: while younger patients were admitted most commonly for trauma or acute respiratory failure, the older groups were most likely to be admitted following liver transplant (primarily for chronic liver disease), metabolic or endocrine disorders, or planned surgery. From the results obtained in the subgroup analysis, it has been seen that the patients from the trauma group suffered the greatest amount of psychological dysfunction as measured by the GHQ, and also had the highest IOES scores, indicating the greatest number of symptoms of PTSD. Lowest GHQ scores came from the unplanned surgery group, while lowest IOES scores were recorded by the planned surgery and the transplant groups. Thus there is also some differentiation among illness groups by way of age, which may partially explain the prediction of more PTSD in younger patients.

It might be surmised that expectations of wellbeing post-discharge in older patients who have experienced illness before, may be lower or certainly less optimistic than those of young people taken by surprise by a life threatening disorder. This is perhaps a generalisation - many younger patients may have met more than their fair share of severe illness by a relatively early age; nevertheless it is possible that in later years we are more fatalistic and less expectant where overall wellbeing is concerned, and take a more phlegmatic or at the very least proportionate view of such aspects as somatic symptoms, social function and symptoms of anxiety and depression. The question of stress and ageing, though not hugely researched, has elicited comment from Lazarus (1999) on the actualisation of viable objectives - that is, coping with stressful events is enhanced by a realistic approach to the inevitable losses which accompany age and an acceptance that our goals will alter. Folkman, Lazarus, Pimley & Novacek (1987) examined coping by different age groups in relation to everyday stress as measured by the Hassles and Uplift scale (Lazarus 1984b). Older participants (65 to 75 years old) were found to appraise situations more positively, attribute more responsibility to themselves, and utilise humour in their coping strategies. In contrast the younger participants

(35 to 45 years) sought out social support more, and were more likely to adopt a confrontive style - try to take direct action to deal with the stress. This particular study centred on sources of stress encountered on a daily basis rather than those specifically related to health and illness, and thus the stress for the two groups differed in nature. Here the original sources of stress, critical illness and ICU admission, were similar for all age groups. Yet the findings of Folkman et al. (1987) may shed some light on the results of this study where younger survivors may be at risk of a poorer psychological outcome - it is possible that the older patients did have a more positive reappraisal style and came out of the experience in a less distressed state. Confrontive coping - as described in the younger of Folkman et al.'s (1987) participants - has been seen as both advantageous and disadvantageous in illness related stress. Some studies report less distress in those with a confrontive style (Affleck et al. 1987, Dunkel-Schetter et al. 1992) while others comment that a confrontive, problem solving approach is not necessarily helpful in coping with the stress of illness (Bombardier et al. 1990). Such studies tend to centre on the more chronic illnesses, which may limit their application somewhat to the study of patients from a critical care setting. Yet the differences observed in the impact of chronic diseases on different age groups can in fact be informative here; the patients in this study do not necessarily suffer from chronic disease in the degenerative sense but they are likely to have some chronic, that is enduring, health problems, for some period of time. Moos (1982) has commented on the contrast in response to disabling chronic conditions, with young adults reporting difficulties related to relationships and career plans while those in middle age are more concerned with adapting their roles and lifestyles, though both of these could conceivably have a negative influence on outcome after critical illness. Meichenbaum & Turk (1987) and, more recently, Bosley et al. (1995) have suggested that younger patients are less likely to adhere to treatment advice, possibly explaining the poorer wellbeing scores here, although there is argument about adherence and others have found no difference in age (Lorenc & Branthwaite 1993).

Theories of illness representations in general may also have some relevance here. Different cognitive dimensions of illness attribution have been described in relation to illness identity, cause, time lines, consequences and cure or controllability (Leventhal et al. 1980, Petrie & Weinman 1997). Of particular relevance is the dimension of the consequences of illness, which include pain and discomfort, social dislocation and economic effects (Edelmann 2000). Petrie & Weinman (1997) have proposed that differences in cognitive representations influence the response to illness, and , again, the different degree of thought maturity as originally suggested by Riegel (1973) may have some effect on the cognitive representations of illness consequences held by different age groups. Do the older ICU survivors have fewer expectations in relation to illness consequences, and hence less distress in the recovery period?

"World view" is considered an important factor in the more recently developed cognitivephenomenological models of stress (Scheier & Carver 1987, Janoff Bulman 1989, Wortman et al. 1992) with differences in outlook, or sets of schemata, accounting for different reactions to stressful experiences. The different degree of dysfunction may be explained by the way schemata alter with age: the more virginal or untainted one's world view, the more distressing or disturbing the stressful life event. Fisher (1984) has described the importance of individual interpretations of reality in adjustment to stressful situations, where the discrepancy between reality and intentions influences the stress perceived by the individual: these ideas have been discussed in Chapter Three. The discrimination afforded by age in this research sample may perhaps be explained in part by Fisher's theory. Individual ambition or intention may be higher in the younger ICU patients than in the older ones, and interruption by way of critical illness and ICU admission viewed as more catastrophic.

One problem highlighted in this area of study (Elder 1974, Folkman et al. 1987, Lazarus 1999) is the imponderable of cohort effect when considering age differences in stress response or coping. This is the problem of unravelling developmental effects from the effects

of different time periods. In any study of different age groups it is likely that those at the older end of the scale have had different experiences to those at the younger end, simply by being raised in different times. Thus values, beliefs and thought patterns might differ according to the cohort, or age group. Here parallels may be drawn in the participating patients' beliefs about illness and intensive care. Older patients may have witnessed more illness, either their own or others, and in the context of "viable objectives" as described by Lazarus (1999) may be less shaken by their experience. It could be that younger patients are taken more by surprise by the whole experience, with a consequently more profound effect on wellbeing. There is though a converse argument which uses the same cohort effect basis; that is that the older patient is more likely to recall a time when medical care did not achieve the technological level that it does today, and thus be taken aback by the ICU experience. Younger patients on the other hand, in an industrialised culture at least, have been raised in an environment where the existence of high technology care is an accepted feature, and they might then be expected to take the experience more in their stride. However if this is so, it has not been the case for the patients examined in this study.

The argument for more distress in the young is expanded by PTSD theory, discussed in some detail in Chapter Four, which offers some more detailed underpinning explanation of this differential finding. The cognitive appraisal approaches adopted by Janoff Bulman (1985) and Epstein (1990) suggest that PTSD may result from the disruption of assumptive constructs engendered by a traumatic experience. Yet by their very nature mental constructs or schemata are highly individual and tailored things. It could be argued then, as above, that difference in age may mean difference in assumptive constructs, which may well become less rigid the older we get. In particular notions such as one's own invulnerability, or a view of the world as a largely benevolent, comprehensible and controllable place, may fade as life's slings and arrows are experienced. With regard to the cognitive changes which occur with age, there has been suggestion that ways of thinking might continue to alter throughout adulthood. Riegel (1973) described the formation of "mature thought" once adulthood is attained. This mature

thought allows the individual to be flexible in his or her thinking, or to see that there are contradictions in life. One such contradiction could of course be, in the context of the ICU survivor, that all reasonable attempts might be made to lead a healthy and risk free life, yet sudden critical illness can still occur like a bolt from the blue. Perhaps the schemata of the older person are able to withstand more damage, resulting in the mismatch being far less noticeable in the experienced or worldly wise older patient than in the naive or idealistic young. Assimilation and accommodation consequently take less time and less effort, with a resultant lower report of PTSD symptoms (if measured).

The information processing model described by Horowitz (1973,1976, 1979), and discussed in Chapter Four, focuses on the discrepancy between world view before and after the traumatic experience: again the intensive care episode may indeed be unpleasantly traumatic and beyond the realms of normal experience for all age groups, but is more likely to have been encountered - via friends or family - by the older patient. Thus it could be surmised that Horowitz's "completion" - the repeated processing of the raw information until reality and schemata match - should take less time for older individuals. More rapid integration then would mean more rapid dispelling of PTSD symptoms of intrusion and avoidance, hence the noticeable difference in IOES scores according to upper and lower age groups.

This is borne out by the psychosocial theory of PTSD (Green et al. 1985) wherein individual variables like previous experience, coping capacity and age, plus such situational variables as social support and the strangeness or familiarity of the trauma context, shape the response to severely traumatic experiences. Again, it could be suggested that greater age is usually associated with greater experience of life and, if not more efficient, certainly more maturely developed coping capacities.

Age then appears to be a distinguishing variable with regard to long term psychological wellbeing (as measured by the GHQ28) and also predictive of symptoms of post traumatic

stress. Its emergence as a predictor of PTSD is an important finding within the study, and one which was relatively unexpected. Rather it might be anticipated that the younger the patient, the more rapidly he or she might recover emotionally from this kind of experience. There may be a tendency to view the younger patient as the more vigorous and resilient - yet, as described at the outset of the study, emotional or psychological recovery does not necessarily keep pace with a return to physical health, and these results suggest that the healing capacity of the young person's body may not automatically extend to the mind.

#### 11:2 Length of stay in ICU

Length of stay in ICU did not emerge from the regression analysis as a predictor of psychological outcome, although in the initial subgroup analysis a shorter length of stay in ICU seemed to be related to a higher GHQ28 score, indicating worse psychological function. This does not support outcome research such as that reported by Kleinpell (1991) who found that a longer hospital stay was associated with greater psychological impact. Yet PTSD symptoms appeared to be more prevalent for the longer staying patients, certainly initially, producing a somewhat muddled picture in relation to length of stay. Length of stay and admission severity are linked, this stands to reason, and the regression results in relation to admission severity scores – discussed below - whereby those who were sicker on admission reported better outcomes, shed some light on the findings in relation to length of stay in ICU.

#### 11:3 Admission severity

Admission severity score, as measured by the APACHE II scale, was found to have predictive value, with a negative regression coefficient, in relation to both psychological function and self-esteem at twelve months. The relationship between admission severity score - and thus degree of sickness - and estimation of wellbeing over the follow up period, is of interest in the

overall examination of recovery. Findings here suggest that the sicker the patient on admission, the better the psychological function, as perceived by the GHQ28, and the greater the self esteem, at twelve months. These findings are at odds with the notion that severe illness is accompanied by a drop in self esteem, as well as refuting previous research linking high admission severity scores and reduced quality of life following discharge (Sage et al. 1986, Goldstein 1986, Yinnon et al. 1989). Within this study the reverse situation was found, with high admission severity scores predictive of good levels of wellbeing and self esteem at the end of the follow-up period.

What explanations can be offered for this finding? One possibility is that the very sick patient who recovers in intensive care may receive particularly intense levels of care beyond the unit: a high input from staff on the receiving ward following discharge from ICU, and regular frequent follow up by both the medical or surgical team via outpatients, and by health professionals in the community. In this way attention levels remain high, the patients' physiological needs are met very fully, and the by-product may be maintenance of wellbeing and self esteem. This argument pertains also to the attention received from the family: the threat of loss can be a powerful motivating factor and it is conceivable that those patients who were severely ill and presumably in gravest danger on admission might receive much support and bolstering on return home, to the benefit of their wellbeing and self esteem. There is some evidence for this notion from studies of social support, whereby the advantages of support are more evident in the patients who have the most illness-induced impairment (Christensen et al. 1989, Littlefield et al. 1990). Again it must be noted that these studies were concerned with renal failure and diabetes mellitus respectively - chronic conditions where parallels cannot always be drawn with the acute conditions often responsible for ICU admission.

The explanation can be extended to the patient's own perception of the illness and recovery. It may be that awareness of a "narrow escape", and of Herculean attempts to save one's life,

have a positive effect on outlook. Support from health practitioners can be beneficial to psychological function after surgery (Schulze et al. 1988), indeed in a study of breast cancer sufferers, strong emotional support from the doctors has been related to recovery of immune function (Levy et al. 1990). As discussed at length in Chapter Five, the key property of quality of life as a concept is that it is a relative matter. The patient's report of wellbeing may be commensurate with his gratitude or relief at surviving this crisis. This has to be a cautious suggestion in the absence of information about premorbid disposition but it is worth consideration all the same.

In Chapter One the use of scoring systems like APACHE was described and it was seen that common criticisms levelled against formulaic outcome prediction have been the absence of intangibles (aspects such as the patient's will to live, or his or her disposition) in the survival equation, and the lack of explicit consideration of psychological state in the outcome. Here then is further evidence suggesting that these factors may be important. The results of this study demonstrate greater wellbeing and higher self esteem in those who were admitted with the highest APACHE scores - that is those who were in worst shape physiologically on arrival in the ICU and who, numerically speaking, had worse prognoses.

#### 11:4 Communication

Within the regression analysis communication failed to attain statistical significance as a predicting variable, although the results of the subgroup analysis had suggested that those who remembered being able to communicate their wishes to others while on the ICU, reported poorer wellbeing and more PTSD symptoms. This single finding may have been spurious, equally there may be some real link. Certainly the finding is at odds with those regarding recall, where complete absence of recall was associated with more symptoms of PTSD during the first 6 months of follow up. However by 12 months the "high recall" group's scores were rising, indicating presence of PTSD, resulting in much less discernible

difference between "high recall" and "no recall". To perceive oneself as able to communicate implies some degree of awareness and recall; possibly the memory of efforts made to communicate with people on the ICU causes some difficulty.

How best to communicate with ICU patients is a question which has been posed by a number of researchers (Ashworth 1980, Harvey et al. 1993, Fontaine 1994). Much attention has been paid, quite correctly, to finding a good and easy method for an intubated patient to convey his or her requirements to the people that matter. Yet the response of ICU staff to the patient who attempts to communicate may also have some bearing on the patient's perception of the experience. Ashworth (1980) described mainly favourable views of staff response in her study "Care to Communicate", though she did note that nurse-patient interactions which were not related to tasks or procedures tended to be quite limited. The Ashworth study is now twenty years old yet there is still concern expressed about awareness of communication needs, and the tendency of some staff to distance themselves from patients, whether through avoidance of involvement or mere pressure of work (Calne 1994). It may be that there are links with some need for control, since absence of control can result in emotional disturbance for some patients (Jones & O'Donnell 1994, Dyer 1995, Lazure 1997).

Nevertheless the literature tends to point to ability to communicate as a positive rather than a negative feature (Harvey et al. 1993, Jastremski & Harvey 1998) and the findings from this study are not easy to interpret. Communication was admittedly measured in a fairly crude form - its measurement involved asking the patients one question about their ability to make themselves understood while on the ICU. Communication was treated as one of the numerous ICU related variables within this study, but will certainly be included, operationalised in a more detailed manner, in follow on research.

#### 11:5 Trauma

Indication for admission, or illness, was subdivided into seven broad areas for the purposes of analysis, though the very wide range of conditions treated in this ICU were described in Chapter Eight. From the subgroup analysis, trauma emerged as the illness associated with worst psychological dysfunction as measured by the GHQ. The regression analysis also suggests that trauma is predictive of poor psychological function and wellbeing as measured by the GHQ at both six weeks and six months follow up. This finding supports those of Thiagarajan et al. (1994) whose critical illness follow-up study reported a decreased level of perceived wellbeing in trauma patients in particular. The trauma involved in an accident - be it road traffic, industrial or sporting - may be intense, but so too may the intensive therapy involved in putting the victim back together again. Very often in trauma cases the body systems disrupted are numerous: bones are broken, skin severely damaged, internal organs ruptured - and these initial problems will be compounded by the consequent life threatening failure of cardiac, respiratory, renal or hepatic function. Further, the average age of the trauma patient tends to be lower than that of ICU patients overall, thus dissent over admission is less likely and administration of all possible treatment - "pulling out of all the stops" much more likely. Trauma patients may be on the receiving end of some of the most intense intensive therapy possible in the ICU, bringing into being all manner of stress which may impact on psychological function after discharge.

In the correlation analysis trauma also correlated negatively with IOES scores at six weeks (p<0.05). It proved not to be a statistically significant predictor of any IOES outcome scores, but it is worth considering briefly again the implications of the association between trauma, and post traumatic stress symptoms in this research sample. It is acknowledged that trauma per se is a distressing, out of the ordinary experience and as such may be the source of intrusive thought and avoidant behaviour. However it can be seen from the methodology description in Chapter Eight that this fact was considered from the outset as having the

potential to taint responses, and great effort was made to avoid its happening. Both the conversation with the patient at recruitment, and the instructions administered with each set of assessments, included explicit requests to consider the ICU experience rather than preceding events.

Theories of post traumatic stress which refer to the shattering of assumptive constructs (Janoff Bulman 1985,1989,Epstein 1990, Wortman 1990) may have some relevance here. In contrast to the exacerbation of an existing, chronic illness, trauma - in the context of hospital admission - is generally sudden and shocking. Many schemata will be simultaneously destroyed. For example those pertaining to the subject's sense of physical health, to the safety of the world around them, and - once they have begun to assimilate - to their future function. The Horowitz model (1979), basis for the IOES, has discussed the mass of internal and external information the trauma victim must deal with and the repeated processing required. This notion may be as relevant to victims of accidental trauma as it is to, say, victims of war.

However the researcher is not so naive as to think that the two concerns - the initial trauma and the ICU treatment - can remain distinct all the time in the mind of the trauma patient, and the importance of recognising PTSD in trauma patients whether or not they are admitted to ICU has been highlighted (Demi & Miles 1983, Brom et al. 1993). The very nature of post traumatic stress means that thoughts and images come unbidden into the sufferer's mind, and dreams which occur during the altered state of sleep are not under our jurisdiction. Nevertheless, if these patients are included in those at risk of poor psychological outcome after discharge then the effects of their ICU experience must be considered alongside those of the original trauma which necessitated admission.

#### 11:6 Muscle relaxants

Use of muscle relaxants, or paralysing drugs, is less prevalent now in ICUs with the advent of sophisticated ventilators. However there are still patients who will receive them, either to treat underlying problems such as seizures, or to combat intractable problems with ventilation. The initial subgroup analysis yielded the interesting finding of lower IOES scores - fewer PTSD symptoms - in the group which had received muscle relaxants, with a statistically significant difference in IOES scores at twelve months. However this failed to emerge as a predicting variable from the regression analysis. The initial result for muscle relaxants, from the subgroup analysis, has been pointed out as possibly spurious especially given the discrepancy in numbers between those who did and those who did not receive the drugs. A golden rule of anaesthetics and intensive care is that paralysing drugs must be given with adequate sedation - to avoid the nightmare scenario for the patient of awareness accompanied by paralysis and inability to alert people to the situation. Assuming good practice then, the patients receiving relaxants were also likely to have been well sedated, which may have contributed to their lower IOES scores. This is another angle which may be expanded in follow on research, since it lies somewhat at odds with the idea that lack of recall leads to dysfunction post discharge.

#### 11:7 Cancer

The variable "cancer" differentiated between those in whom cancer was part of the original problem prior to admission, and those in whom no malignant disease had been diagnosed. This was in an effort to tease out any problems which might arise in the patients who had been facing a potentially life threatening illness before their condition was compounded by a

critical period necessitating ICU admission. The notion of shattering of constructs was proposed in Chapter Nine in the discussion of the emergence of cancer as a discerning variable.

In the subgroup analysis the cancer group had significantly lower IOES scores at 6 weeks and 6 months, and in the correlation analysis there was a significant negative correlation between cancer and IOES scores at 6 weeks, implying that the presence of cancer was associated with fewer symptoms of PTSD. The regression analysis identified cancer as a predicting variable, with a negative coefficient, for IOES scores at six weeks. The indication was that those patients for whom cancer was a pre-existing problem were likely to have fewer PTSD symptoms. This finding is of considerable interest, and it directs attention to the possible importance of experience and cognitive dimensions of illness. Petrie & Weinman (1997) have suggested that responses to illness may vary as a result of different cognitive representations. As discussed earlier, in Chapter Nine, this patient group is likely to have been subjected to quite radical treatment before arriving in the ICU, and schemata in relation to hospital admission and treatment may well be considerably different to someone who has not followed the route of the cancer patient. Certainly this is a finding which could be of use to those developing and targeting ICU follow up services.

#### **CHAPTER TWELVE: CONCLUDING DISCUSSION**

"What's past is prologue; what to come, in yours and my discharge"

William Shakespeare, The Tempest, Act II Scene 1, 253-4.

#### 12:1 Overall picture

Recovery from critical illness can be hard work, very often requiring considerable readjustment to physical incapacitation. It seems that psychological recovery may be equally taxing, and its progress not nearly so swift. Overall this work has shown that long term emotional wellbeing is indeed compromised in some measure after discharge from ICU; specifically it has demonstrated psychological dysfunction, low self esteem, and symptoms of post traumatic stress in the sample of patients involved. At the same time it has shown that these three aspects of dysfunction, as measured by the tests used, are strongly linked with one another (see Appendix XIV). In addition to demonstrating the potential for problems post discharge - as evidenced by some of the higher GHQ and Self-Esteem scores, and by the percentage of patients with PTSD symptoms - the research has shown that recovery is not necessarily a matter of gradually diminishing symptoms, but may involve highs and lows in the year after discharge.

The general pattern of outcome scores, described in Chapter Eight, showed that psychological function as measured by the GHQ increased slightly between six weeks and six months, then decreased again by twelve months. Self esteem, as measured on the Rosenberg scale, followed a similar course. Symptoms of post traumatic stress as measured by the Impact of Event scale, showed a gradual diminution over the entire follow up period. This fluctuation in

psychological wellbeing over a twelve month period is to be expected, it would be unusual to find perceptions and coping remaining absolutely static over a year following a distressing event. Possible explanations for the seesawing of recovery are suggested below. Although these are primarily surmise at this stage and would need to be supported by further study, they are an attempt to map some of the findings of the study on to the overall pattern which emerged from the data obtained. It is important though to repeat that, in this sample, no significant change in scores, for the GHQ, SES or IOES, was seen over time (see Table 8f for Wilcoxon tests on total scores). This indicates that, even though some variation in psychological function existed in this group of survivors, overall there was no statistically significant improvement or deterioration in scores as the year progressed.

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### Table 12a: Suggested explanations for overall recovery patterns.

Time post-discharge	Patients' experience			
Six weeks	Still physically unwell, tired.			
	Treatment, drugs not fully taken effect.			
	Social / family support at a maximum.			
	Impact of experience not wholly absorbed.			
Six months	Physical recovery progressing.			
	Becoming accustomed to treatment, hospital visits.			
	Drugs have taken effect.			
	Social support continues (though perhaps less intense).			
Twelve months	Permanent changes in lifestyle have impacted.			
	Social support waned, family weary?			
	Hospital follow up probably reduced or ended.			
	Experience further integrated, but status as "sick" faded.			

The identification of post traumatic stress symptoms has been of particular interest. As described in Chapter Eight, the percentages of surviving patients reporting a medium level of symptoms, a global indication of problems (Horowitz et al. 1981), were 27%, 20% and 26% at first, second and third follow up points respectively. Those reporting a high level of symptoms, at a level deemed by Horowitz to merit concern and possibly indicate pathology, were 39%, 32% and 26% at first, second and third follow up points. These figures imply that over half of the patients in this sample were experiencing symptoms of post traumatic stress, a year after discharge. The Horowitz model emphasises the massive amount of both internal and external information presented to the individual during a traumatic experience. Using the terms of the model, it appears that for a substantial number of patients in this study, attempts to process the overload of information were still incomplete by the twelve month point, resulting in continued intrusion and avoidance as completion of processing occurs.

The results of this study reflect the reported average rate of PTSD following a traumatic event which Green (1994) calculated at 25% to 30%. They also support the findings of the few studies of PTSD in ICU survivors, matching the findings of Schelling et al. (1998) who found a 27.5% incidence of PTSD in survivors of Acute Respiratory Distress Syndrome (ARDS), though as discussed earlier ARDS may carry with it particular risk of affective and cognitive impairment consequent to the prolonged and severely hypoxic state it causes (Hopkins et al. 1999). The rate of PTSD found in the present study is greater than that identified by Koshy et al. (1997) where 15% of patients surviving ICU reported symptoms.

The results of the study have been examined in the light of cognitive theories about PTSD, such as those suggested by Horowitz (1979) and Janoff Bulman (1989). The notions of shattered assumptions, reprocessing of traumatic experiences, and restructuring of constructs can feasibly be applied to the experiences of these patients and are particularly helpful in understanding the length of time symptoms take to resolve.

Equally the psychobiological perspective offers useful explanations with regard to some of the physiological changes effected during the ICU experience, and this approach too must be of interest in future research. The author suggests here that the neurochemical changes accompanying stress may be compounded by the drugs administered within intensive care. Supportive therapy frequently includes infusion of adrenaline, noradrenaline and other inotropic drugs, that is drugs which will support the circulation during cardiogenic shock. In addition, cortisol based drugs are regularly administered. Given the involvement of neurochemistry in stress, and perhaps in the post traumatic stress response, as discussed in Chapters Three and Four, it is feasible that altered levels of catecholamines and cortisol may interfere with storage and consolidation of memory for the ICU experience. If, as is suggested by the studies discussed in Chapter Four (McGough & Gold 1989, Cahill et al. 1994, Hagh-Shenas et al. 1999), memory systems are influenced by naturally occurring raised levels of circulating catecholamines and hormones, what changes might be wrought by the vast extra doses administered therapeutically? Though not addressed within this study, this point has been raised by the author with a researcher in the area of PTSD, who agreed that the potential for infused adrenaline and noradrenaline to affect post traumatic states should not be discounted (personal communication, Neal, 1998).

Whatever the underpinning factors, the important thing at this stage is to acknowledge the incidence of PTSD. Green (1994) has suggested that up to 50% of those diagnosed with PTSD after a traumatic experience may continue with symptoms for a number of years. This assertion lends strength to the argument that symptoms should be recognised in ICU survivors and intervention offered if required. It has been suggested that many patients do not disclose emotional distress unless questioned specifically by an interviewer, or given the opportunity to respond to a questionnaire (Maguire 1980, Palmer 1980). The author would support such views, and although it is not possible to exclude entirely the hazard that, in some individuals, distress may be provoked by questioning, this must be weighed against the risk of patients

suppressing problems because they think they are quite alone in experiencing psychological symptoms.

#### 12:2 Variables excluded from the regression analysis.

Although length of stay in the ICU demonstrated a significant relationship with outcome, length of stay in hospital overall, displayed a much weaker relationship. As discussed in Chapter Nine, the results of the subgroup analysis suggested some differences in PTSD symptoms at six weeks, with more symptoms reported by the group staying longer in hospital after discharge from the ICU. However the outcome scores had levelled out by twelve months and few differences were detected between groups by the end of the follow-up period, indicating that the stay in hospital overall may be less important to psychological outcome than length of stay in the ICU itself.

Though not attaining statistical significance, the results in respect of recall in the subgroup analysis raised interesting points. Within this research sample, the greatest amount of psychological dysfunction arose in those patients who had no recall for the experience, markedly refuting the suggestion made by Cheng (1996) that deliberate suppression of recall and awareness during ICU treatment might guard against emotional and psychological problems following discharge. The findings from this study suggest rather that recall of the ICU experience may in fact be a desirable thing rather than something to be avoided, confirming recommendations made by others in the same field (Jones, Humphris & Griffiths 1998, Backman, Johansen & Walther 1998). A finding of particular note was that amnesia for events is not necessarily associated with a good outcome, here a number of patients with no real recall nevertheless reported symptoms of PTSD. This raises questions about the nature of PTSD, or at least about the aspects being tapped by the Impact of Event Scale - questions beyond the scope of this study at this point but well worth further research.

State dependence - information retrieval occurring more readily when the central nervous system state matches that which pertained during learning - may be a factor in relation to recall

of the ICU experience. However this might be difficult to ascertain: returning the subject to the ICU bed or cubicle, or readministering the cocktail of drugs used, would clearly be a hazardous ,unethical and highly impractical undertaking. Yet within are traces of potential: for example, a number of units which have developed ICU follow up services tend to stress their deliberate move to meet surviving patients away from the unit itself, in order to minimise unpleasant associations. For those patients who have struggled to piece together information, yet feel a need to complete the puzzle of the experience, state dependent recall may hold some possibility. The lack of consonance between the patient's alert, fully conscious state when answering questions about recall, and the hazy mental state of the illness period, may reduce information retrieval quite considerably. Return to the ICU, with its particular smells and sounds, could conceivably trigger memories which instead of representing threat, reassuringly fill some of the gaps in the survivor's impressions of the whole episode. The author's experience with grieving relatives has suggested that return to the late patient's ICU bed or cubicle can have beneficial effects, either by way of catharsis, or by encouraging an adjustment to the unhappy reality that their relative has truly gone.

The author has recently participated in the newly developed ICU follow up clinic at the research setting hospital. The experience thus far has supported the ideas of Jones et al. (1998) and Backman et al. (1998) quoted above, that is that recall of the ICU is not particularly something which should be suppressed. Indeed the patients whom the author has met and listened to seemed to experience some relief at describing what they could remember, memories which included all the senses. Apropos the siting of follow up clinics, this new local clinic is currently being held in the outpatients' department. Interestingly, of the ex-patients seen thus far, more than half have expressly asked if they may go up and visit the unit and the staff, and an extra member of staff has been deployed to escort ex-patients to

and from the ICU. The practice of offering follow up in close proximity to the ICU, as opposed to in some distant outpatients' clinic, should perhaps be given serious thought.

The findings related to social support produced no statistically significant results, but the trend did bear out the observations of a number of researchers such as Cobb (1976), Brown & Harris (1978), Schaefer et al. (1981) all of whom have reported beneficial effects of social support in relation to stressful events. Oatley (1988) has suggested that a low level of social support may disadvantage those recovering from stressful life events, in that they may struggle to reconstruct some sense of self worth in the absence of any close relationships. This is borne out by the findings here, where those living with next of kin reported improved self esteem over the follow up period, those with more moderate levels of support had fairly stable self esteem, and those patients with minimal support reported a reduction in self esteem over the follow up period. The finding of higher levels of PTSD in those with no perceived support is potentially of use clinically, though the small numbers dilute the findings. The advantages and disadvantages of social support in relation to stressful events have been discussed. Certainly in this study a higher level of support was associated with better psychological function and fewer PTSD symptoms; social support could perhaps be explored in more depth when assessing patients for discharge, with attention paid to both structural and functional aspects. In this way the perceived quality of the social support available would be better assessed, allowing perhaps more accurate conclusions to be drawn regarding relationships between support and outcome.

Sleep, and occupational classification as differentiating variables yielded little useful information and their results have been discussed in Chapter Nine in relation to the subgroup analysis.

In the matter of different indications for admission, or illness groups, the emergence of trauma as a predicting variable has been discussed, and the importance of considering PTSD

in this group is highlighted, in relation not only to the original traumatic incident but also to the period spent in the ICU. The results here suggested the possibility that this group of patients could suffer a degree of psychological dysfunction after discharge which might constitute "caseness" on the GIIQ28 scale. Useful information about liver transplant patients also emerged - this group displayed an interesting picture of initially good wellbeing and minimal psychological dysfunction, followed by some deterioration over the year after discharge. The possible reasons for this pattern have been examined; in fact the transplant patients probably attend for more intensive follow up than any of the other illness groups. Liver transplantation, and multi-organ transplantation, are rapidly developing areas of care with specialist interest groups and a growing volume of literature. The author has retained clinical links with the Liver Transplant Unit involved; the results of the study have been discussed with and will be made available to the unit.

In the analysis of mode of admission, poorest psychological function according to the GHQ, and lowest self esteem, were displayed by the patients who had been admitted conscious to the ICU, though as previously stated this diminished to a very small group. The IOES indicated that the most post traumatic stress symptoms were also reported by patients admitted in a conscious state, and the possible explanations for this finding have been discussed following the initial analysis. This was one of the variables which yielded less discriminatory function than was hoped. It was included in the data collection as it has not featured in research into outcome, and was felt to have potential as a differentiating variable. The findings did not allow the drawing of any clear conclusions, especially since the difference detected in the subgroup analysis could not be confirmed by post-hoc testing. The very small numbers in the "conscious" group may well have been a problem here.

Given the minimal influence one can have over mode of admission, it may be that the inconclusive results could be seen in a positive light - it would after all be nigh on impossible to dictate that patients be admitted via one or two particular routes because their

psychological recovery may be affected, and the dangers have been mentioned earlier of an over zealous or idealistic approach to risk identification in relation to psychological recovery. Possibly the most which can be hoped for is that ICU staff remain mindful of the potential distress associated with conscious admission to the ICU, and therefore continue to act accordingly.

Sex of the patient produced no notable differences, though the initial analysis suggested that by the end of the year of follow up men might be in a slightly worse state psychologically than women. The presence of relatives during the stay in ICU also proved a non-starter as a significant variable, though again the initial analysis suggested that it was a beneficial factor as far as outcome goes.

Finally coincidental life events were considered. This variable was included to ensure a clear picture of the follow up period: in fact pivotal events were few and far between in the reports of those patients who survived the twelve months. Those which were recorded included moving house, death of a relative or friend, and one participant's report of a decision to retire from work. The subgroup analysis offered the not unexpected finding that outcome was slightly better for those who did not experience coincidental events during the follow up period, but the variable did not display significant influence beyond this stage of the analysis.

## 12:3 Strengths and weaknesses of the study.

A number of extremely useful findings have been made in the course of the study, but clearly caution is recommended in the interpretation of the results. The strengths and weaknesses of the total patient sample/ research design have been discussed in Chapter Seven which dealt with the methodology. Among the strengths mentioned were:-

- The study took a longitudinal approach which, though time consuming, generated a large volume of data from which to build a picture of recovery. The issue of long term psychological problems was identified as a result of considerable clinical experience with critically ill patients in several different ICUs, and conjectures had been made about potential influencing factors. It is clear from the literature review that, although the psychology of ICU patients has spawned a large body of literature, long term psychological outcome has been one of the sparser areas of research, and this study generated a considerable amount of information pertaining to a relatively long follow-up period.
- The psychometric assessments were chosen for suitability to the patient group and had been validated in previous work for use in relation to acute illness. The rationale for the combination of assessments used - namely a generic measure, a self esteem measure and a measure specific to PTSD - was based on theories of stress and PTSD, as well as on the gaps identified by the literature reviews.
- The entry criteria were developed in part to ensure valid use of these assessments. These were: age over eighteen years in particular for use of the GHQ, no known history of psychiatric disturbance, and an ability to read and to understand English language. The clinical experience of the researcher also ensured that flaws were avoided at the recruitment stage as far as possible; it was recognised that certain conditions were likely to be accompanied by compromised cerebral function states such as hepatic encephalopathy, lengthy periods of hypoxia or hypoglycaemia, or toxicity from certain drugs may have affected patients' psychological states and thus a number of potential subjects were eliminated. This did of course have the disadvantage of keeping recruited numbers down so that the final sample was relatively small.

Possible weaknesses in the design include the following:-

• The sample size was undoubtedly a problem in some of the analyses. The constraints of conducting the study with a single researcher meant that the original sample was relatively small, seventy-two patients. Sample attrition then occurred as a result of various factors, discussed in Chapter Eight (Section 8:2). The principle cause for diminishing numbers was death of patients either before follow-up commenced, or between follow-up points; these accounted for the loss of 19% of the sample and this is of course a problem inherent in such a fragile group. A further 15% had to be withdrawn either through their own choice or the researcher's decision, as itemised in Chapter Eight (Section 8:2). The diminution of numbers was compounded by a failure to respond from 12.5% - a reasonably low failure rate in terms of postal survey but nevertheless significant to this sample size.

The consequence of this loss of patients was small numbers when subgroup analyses were performed, and as can be seen in Chapter Eight, categorising of the subgroups had to be collapsed in some variables in order to increase group sizes where very small numbers were involved. Smaller sample sizes carry the likelihood of larger sampling error, and a larger sample size may have counterbalanced any atypical values within the data, though larger samples too may contain bias (Polit & Hungler 1993). Tabachnick & Fidell (1989) urge caution in analysis of variance tests, when group sizes are different, since inequality of variance can sometimes spuriously increase significance levels. In the post-hoc testing for the subgroup analysis, the use of multiple pairwise comparisons was avoided since it would have raised the possibility of Type I error; instead the Mean Rank Sum test was calculated where Kruskal Wallis testing had detected between group difference. In cases where posthoc testing failed to confirm any significant difference between separate groups, the Kruskal Wallis finding was discounted as spurious. To reiterate, cautious interpretation of results is therefore necessary.

- The change of approach was also discussed and acknowledged in Chapter Ten, as a potential weakness in relation to regression analysis following non-parametric subgroup analyses. There have been comparatively few previous studies to rely on in this particular field where such a wide variety of ICU related variables has been investigated in relation to long term psychological outcome, particularly for any predictive property. Logistic regression analysis was undertaken to search for predicting variables; it is seen as particularly suitable where the independent variables comprise a combination of continuous and categorical variables (Field 2000), as was the case in this study. Tabachnik & Fidell (1989) have suggested that this approach to predictive modelling may be less likely to violate parametric assumptions. However, results obtained from multivariate analyses should be interpreted with caution where the variables entered are of this nature: that is, quantifications of processes which may qualitatively vary, such as psychometric assessment scores which are context dependent. It is accepted that conclusions may be undermined if an assumed model is not an accurate representation of reality.
- Also in relation to methodology, it is accepted that the methods used to analyse the data could be seen as using maths for maths' sake that is a preoccupation with using subgrouping, correlation and regression to generate information which might be produced in a more qualitative fashion. The intention of the study was, though, to attack the problem of psychological recovery post ICU using a different approach to those used elsewhere, by attempting to unravel matters and search for associations numerically. The quantification, and subsequent quantitative analysis of psychological outcome, was done with underpinning clinical knowledge and some prior notion of the possible influencing variables. This meant that the interpretation of the initial analysis, and the inclusion of the variables in the regression, made sense in a clinical context. Certainly the results have enlightened the author; as discussed earlier, the exact equations are of less importance than the patterns they represent, and the information they convey, about factors which are

relevant to the patient's recovery and about possible explanatory mechanisms for individual responses to the ICU experience.

- The question arises as to whether the study sample is representative of ICU patients in general or has suffered unduly from selection or referral bias? That is, does the pressure on beds in this University Hospital ICU mean that only the absolute sickest patients are admitted, resulting in a sample biased towards more severe cases? If this were the case then very careful consideration would need to be given, in particular to the finding of admission severity scores having predictive value, since these might be greater than comparable admission severity scores in other ICUs. However, the pressure nationwide on ICU beds has been discussed already, and this is probably not an extraordinary ICU, its practices, its pace of activity and case mix notwithstanding.
- It is possible that the entire episode of illness may have affected the patient's cognitive abilities and thus influenced responses to the questionnaires in some way. As described in the methodology chapter, care was taken to ensure that patients likely to have sustained cerebral damage were not recruited to the study, but it is accepted that this was not entirely foolproof. Yet the responses made by the participants at each stage of the follow up represented reality for the patient at that point in time, whatever their cognitive performance, and perceived psychological state was after all the focus of the research. Cognitive impairment has been measured formally by studies of neuropsychological consequences of cardio-pulmonary bypass surgery (Taylor 1982, Mills & Prough 1991) where, as discussed in Chapter Two, the bypass process itself can lead to cognitive impairment in survivors of Acute Respiratory Distress Syndrome (ARDS), also discussed in Chapter Two. Here 100% of the sample demonstrated impairment straight after discharge, and at a year 78% still had problems in at least one area. As with bypass surgery, the nature of ARDS may itself cause cerebral damage. It would be of interest to

see further cognitive studies of this kind, if only to form a clearer idea of the kind of problems faced by survivors, and to be able to offer informed comment to patients and families who notice, and may be alarmed by, cognitive changes post discharge.

• Naturally the design and scale of the study do not allow deductions about psychological outcome for all ICU survivors discharged from units across the country. Yet the observed frequency of negative outcomes, even in this relatively small study, certainly highlights the need for consideration of patient psychology in the critical illness trajectory. The pattern of recovery demonstrated by these data goes part of the way to explaining psychological recovery by reducing it to some of its components. The components may have been itemised by the researcher based on ICU related variables which "happen" to the patient; likewise clinical experience may have indicated the likely magnitude and direction of the relationship between variables - though recall and admission severity produced unexpected results - but statistical analysis has demonstrated the relative importance of each.

In discussing weaknesses it is important to reiterate a point made in Chapter One, the introduction to the study, that is that one major extraneous factor which was not measured was each patient's disposition. This might be seen as a truly confounding variable. Nevertheless it is argued here that it is still important to search for important variables which influence outcome. The patients admitted to the ICU come from all over the region, with a variety of problems, and on discharge must return from whence they came to try and recover - whatever their disposition. Disposition, or personality characteristics, are undoubtedly factors for consideration, but in the absence of their formal measurement we can still glean helpful information from many other variables. Indeed it could be argued that some aspects of disposition leak through in the responses given, although this is a tenuous argument given the generality of the assessments used.

## 12:4 Outcomes and recommendations

How then can the findings reported be used to improve practice in relation to Intensive Care? As well as confirming that psychological dysfunction occurs in this patient group, the study demonstrated differentiation among certain subgroups, and, further, it has shown that it may be possible to predict the degree of psychological dysfunction from a few variables. At the close of Chapter Nine a detailed picture was presented of the factors associated with good or bad psychological outcome after intensive care (see Table 9a). Following the correlation and regression analysis it became possible to see a more refined picture of the conceivable influencing factors. Of all the variables included, the following emerged as being of most significance within this study:-

Age Older patients may have a better psychological outcome than younger patients.
 Admission severity Patients who are sicker on admission to ICU may have a better psychological outcome than those who are less sick.
 Illness Trauma, as an indication for ICU admission, may be associated with a worse psychological outcome than other conditions.
 Cancer Cancer, as a pre-existing condition, may be associated with a lower possibility of post traumatic stress.

Four variables out of the large number initially recorded and analysed seems small. Yet what this tells us with regard to surviving patients is potentially of considerable use. Here are four fairly major aspects which can be easily assessed on admission and, more important, easily remembered on discharge. Three of the four actually convey the opposite of what might be expected - first, that younger patients are more likely to suffer from psychological dysfunction after discharge, secondly that a milder degree of severity of admission is no protection against dysfunction later, and thirdly that having a known malignancy before admission may reduce the chances of post traumatic stress after discharge. From these results a greater age, a higher degree of sickness on admission, or pre-existing cancer may be associated with a better outlook psychologically speaking. All patients could be offered follow up, but those who are younger or have been involved in trauma might merit particular attention. It is slightly harder to formulate a plan based on the findings regarding admission severity, nevertheless one can be alert to the fact that the severity of the patient's condition on admission is not positively correlated with the severity of psychological problems after discharge.

Age, admission severity, incidence of trauma and pre-existing cancer are the variables highlighted by the regression analysis, yet the information gleaned from all the other variables need not be jettisoned. Enough has been said about the risks and imponderables of setting complete store by the statistical analysis. It has given a structure to the research notions held prior to the study, but the results generated by the exploratory examination are also of great interest. A number of variables allowed differentiation and can inform follow up practice - factors such as communication problems, recall, social support, and mode of admission. Working with these findings, a checklist of aspects of the patient's experience could be completed which would provide an overview of possible risk factors for poor psychological outcome. In this way, those caring for the surviving beyond intensive care and back in the community can weigh up the potential for psychological problems in their patients.

The timing of offered help is also important. The general pattern of recovery here suggested that overall wellbeing and self esteem were at their worst in the initial recovery period measured at six weeks - and then again at the end of the twelve months. At six months scores on the GHQ and the SES decreased slightly indicating some improvement. PTSD symptoms generally were at their highest level at the first follow-up point. Certainly these results corroborate the practice of seeing patients fairly soon after discharge, around the six week point. This is the time when they can not only be examined physically, but can also spend time talking about their time in the ICU and filling some of the gaps, to help put the experience into context.

Prediction and prognostic models are all very well, but if incorporated into patient management, can they alter outcome? This argument has been examined in part in Chapter One in relation to physiological prognostic indicators. It is suggested here that psychological indicators can enhance the management of patients leaving intensive care. Though it is unrealistic to expect any kind of tool to replace entirely clinical judgment in decision making, an estimate of the likelihood of psychological problems is a useful provision. It supplies additional knowledge to that produced by biomedical approaches, which we have seen explain only some of the variance in outcomes from an experience like this. If the patient is fortunate enough to attend a formal ICU follow up clinic the information may guide care; in any case, some record of possible contributing factors can go with the patient to the receiving ward, and thence to the primary health care team. In the absence of formalised follow up services a record would surely help to improve the *ad hoc* psychological care described by so many.

Management decisions often require complex processes and the assessment of numerous factors. Information about the patient's psychological state is an important adjunct to information about his clinical state. Just as the intensity of physiological management within ICU alters according to prognostic scores, so the intensity of psychological management may need to vary in relation to degree of emotional risk. Though an unduly pessimistic outlook on recovery is not advocated, neither is a Pollyanna approach particularly desirable. There is a danger that, through shortage of time and resources rather than insensitivity, management post discharge will be influenced by the health practitioners' - medical and nursing - perceptions of patient outcome. Without doubt the quality of survival, both physiologically

and psychologically speaking, is hard to predict, notwithstanding the scoring systems and predictive equations developed to date. In section four of Chapter Five the author used the phrase "psychological triage" when discussing predictive scoring systems. This study has generated the means to apply triage, in an informed manner, to psychological risk factors in ICU, and to make predictions about the quality of outcome after intensive care. The results of the research should be primarily regarded as interesting hypotheses until verified by other studies; the predictors identified may well be of value but do need to be replicated in other clinical settings. A number of interesting differences and trends have been reported despite failure to reach statistical significance, but they are not regarded as yet as established findings and their status as mere trends is reiterated.

The study was very time consuming, and logistically complex for one researcher, but it has been worthwhile. It has demonstrated the importance of using different methods and approaches to yield new insight to the problems of this ever expanding patient group, and has laid the foundations of some strategies to temper the impact of the whole experience. The research has contributed towards better awareness of the impact of intensive care, with a view to improving outlook for ICU survivors. At the same time it has emphasised the key role for psychology research in the continuing development of intensive care.

Those patients at risk of poor psychological outcome are in need of targeted intervention or preventative measures and there is a definite need for further studies focused on the interventions possible for high risk patients, including one in the same research setting, informed by the findings of this study. The next phase of this research could well be an examination of the effect of providing follow-up carers with information about expected psychological outcome. Supportive, informed care is no doubt on offer to some patients anyway, and this is not an attempt to deny or replace the invaluable support many receive from family, friends and health practitioners. Rather the study has been undertaken in an effort to improve matters. The research has uncovered a number of problems for surviving

patients which might not, in the general scheme of follow up care, have emerged in discussion with the relevant practitioners. This is, in all probability, the study's most important achievement. What is past, for ICU patients, is indeed prologue: a traumatic episode which has set the scene for a their return to a functional life. Anticipating, recognising and alleviating the difficulties which can arise is the work which is "in yours and my discharge" - the script for an improved psychological recovery may be in the hands of intensive care researchers.

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#### **APPENDICES**

- I. Consent from Ethics Committee and Intensive Care Unit
- II. Patient information sheet and consent form.
- III. ICU datasheet
- IV. Letters sent at follow up points
- V. General Health Questionnaire, 28 item version.
- VI. Rosenberg Self Esteem Scale.
- VII. Impact of Event Scale and consent from author.
- VIII. Life Events form.
- IX. General score patterns (1.) General Health Questionnaire (2) Self EsteemScale (3) Impact of Event Scale
- X. Patients who died during follow up: case mix.
- XI Subgroup statistics.
- XII. Subgroup statistics with missing values treated listwise for comparison.
- XIII. Test statistics and significance levels: subgroup analysis.
- XIV. Spearman correlation coefficients among total scores: General Health Questionnaire, Self esteem scale, Impact of Event Scale.

## APPENDIX I:

# CONSENT FROM ETHICS COMMITTEE AND INTENSIVE CARE UNIT.

Telephone enquiries, please contact Ann Prothero 429

AP/LSD Our Ref: \_\_\_\_\_Your Ref: \_\_\_\_\_

Date: 5 January 1994

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Ms J Perrins, 28 Foxhill Crescent, Leeds, LS16 5PD.



*Leeds* HEALTHCARE

For the good of your health

Dear Ms Perrins,

Project no 1682: Assessment of the long term psychological outcome for survivors of the critical care experience

I am pleased to confirm that the above-named protocol has been approved by the members of the Clinical Research (Ethics) Committee.

The Committee would be very interested to receive a copy of the your findings at some future date.

Yours sincerely,

Stable P

If P R F DEAR Chairman Leeds Healthcare/St James's University Hospital NHS Trust Clinical Research (Ethics) Committee

c.c. Dr M Daly

### The Intensive Care Unit St James's University Hospital Beckett Street, Leeds LS9 7TF Tel 0532 433144 x 5890 Fax 0532 837060

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12 December 1993

Faculty of Health and Social Care Leeds Metropolitan University Leeds

Dear Sir

#### re: Joan Perrins - Research Degree.

This letter is to confirm support for the research degree to be submitted by Joan Perrins. Access to the required patients and any other help I can offer is assured.

Should you require any further information please feel free to contact myself directly.

Yours sincerely

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Nigel R. Webster BSc MB ChB PhD FFARCS Consultant in Intensive Care.

# APPENDIX II:

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# PATIENT INFORMATION SHEET AND CONSENT FORM.



#### INFORMATION SHEET FOR STUDY PARTICIPANTS

You have been invited to participate in a research study of patients who have required intensive care in hospital. The research will look at how quickly you recover your emotional wellbeing following your experience in the Intensive Care Unit.

Several days after you have been transferred out of the Intensive Care Unit the researcher will visit you on the ward to tell you about the study and give you an information sheet.

If you agree to be involved in the research, you will be asked to complete some forms approximately six weeks, then six and twelve months following your discharge from hospital. These should not take you more than about ten to fifteen minutes each time. The forms can be sent to you by post - a paid reply envelope will be enclosed - or if you prefer the researcher will visit you at home to complete the forms with you.

Information will be strictly confidential and will be available to members of the research team only. Individual results may be included in the research report but under no circumstances will your name or any identifying characteristics be included in the report.

If you require further information please discuss concerns with the researcher or contact the number below. If you are happy to participate in the study then please sign the declaration below:

I am willing to participate in this research study. I understand that my participation is voluntary, and I am free to refuse to answer any questions. I further understand that I am free to withdraw from the study at any time, and that this will in no way prejudice my future treatment.

Signed:	Participant	• • • • • • • • • • • • • • • • • • • •
	Researcher	· · · · · · · · · · · · · · · · · · ·
	Date	

The researcher, Joan Perrins, can be contacted via the Intensive Care Unit at St James's Hospital, Beckett Street, Leeds LS9 7TF. Telephone 0113 2837011; or at Leeds College of Health, Telephone 0943-876151 ext.6223 APPENDIX III:

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ICU DATASHEET

## OUTCOME STUDY: ICU ADMISSION.

Name			DOB	Age
<u>Address</u>				<u>Hosp.No.</u>
<u>Telephone</u>				
<u>Sex</u>	1 2	male female		
<u>Occupation</u>			<ol> <li>Professional</li> <li>Managerial &amp; Tech</li> <li>Clerical/Minor supe</li> <li>Semi-skilled manual</li> <li>Unskilled manual</li> <li>Student</li> </ol>	ervisory
<u>Consultant.</u>				
GP.			<u>Address</u> .	
Patient conser	nt ob	tained?	Consul	tant approval for study?
Next of kin			Aware	e of study?

.

Admission date	1. To SJUH
	2. To ICU
Discharge date	1. From ICU
	2. From SJUH
Length of stay	(a) ICU days
	(b) SJUH days
	(-)

Mode of admission ICU	1 Elective with preparation.
	2 Conscious via ward
	3 Unconscious via ward
	4 Conscious via A/E

- 5 Unconscious via A/E
- 6 Via operating theatre

Reason for admission				
1	Respiratory failure/insufficiency			
2	Cardiovascular failure/insufficiency			
3	Trauma			
4	Neurological emergency			
	Metabolic/endocrine emergency			
	Transplant surgery			
8	Surgical emergency			
Malignant disease?	1 Yes 2 No			
Relatives present?	1 Yes 2 No			

Bereavement/others injured?	1 Yes	2 No

## Day 1 APACHE score

### Ventilation

Days	Modes	1	SIMV
------	-------	---	------

- 2 Jet
- 3 Other

Weaning period

•

Re-intubation required		l Yes	2 No
Drugs administered			-
Analgesia		Sedati	ion
Muscle relaxants		l Yes	2 No
Communication during venti	lation	1. Good	2 Poor
Relatives resident		1 Yes	2 No
Date transferred to ward.			
Time from extubation to tran	ısfer .	days	
Recall of ICU		recall ne vague recall h recall	
Sleep on ICU	2 Rea	od amount sonable amoun r amount	t

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Social support

- 0 Lives with next of kin
- Lives whith host of kin nearby
   Lives alone next of kin nearby
   Lives alone no support

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Remarks.

**APPENDIX IV:** 

LETTERS SENT AT FOLLOW-UP POINTS



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INTENSIVE CARE UNIT

3 June 1996

Dear Mr

You recently kindly consented to take part in a research study based at St James's Hospital, Leeds. The study aims to improve our knowledge of emotional and mental recovery after the experience of admission to, and treatment within the Intensive Care Unit.

. . . . . . . . .

Enclosed is the first set of questionnaires for you to complete -please try to answer all the questions according to how you are feeling <u>at this stage</u> following your recent time in Intensive Care. All information will be strictly confidential: although individual results may be included in the research report, under no circumstances will your name or any identifying characteristics be included.

A paid-reply envelope is enclosed for return of the questionnaires. Thankyou again for agreeing to take part in this research study - your response is greatly appreciated. I hope that you are progressing well.

If you have any queries I can be contacted at the University of Leeds School of Healthcare Studies on 01943-876151 ext.6223, or via the Intensive Care Unit on 0113-2837011.

With best wishes,

Yours sincerely,



INTENSIVE CARE UNIT

30 September 1996

Dear Mr

Earlier this year you kindly consented to take part in a research study of emotional wellbeing following treatment in the Intensive Care Unit. Thankyou very much for returning the first set of forms.

I hope that you are progressing well, both physically and emotionally. I hope too that you remain willing to take part in the study, which is yielding interesting and useful information about recovery following discharge from Intensive Care.

I enclose a second set of questionnaires: please try to answer as accurately as possible with regard to your feelings <u>at this</u> <u>stage</u> of your recovery.

As before, the information will remain strictly confidential. I enclose a paid reply envelope for return of the forms. Many thanks for your participation in this research study - your response is greatly appreciated. If you have any queries I can be contacted at the School of Healthcare Studies on 01943-876151 ext.6223, or via the Intensive Care Unit on 0113-2837011.

With best wishes,

Yours sincerely,



INTENSIVE CARE UNIT

10 March 1997

Dear Mr

I last wrote to you in September 1996 regarding the study of emotional recovery following admission to the Intensive Care Unit: thankyou once again for returning the completed questionnaires. hope you have continued to make a good recovery, both physically and emotionally, and that you remain willing to take part in this research.

I enclose the final set of questionnaires. Please try to answer as accurately as possible with regard to your feelings <u>at this</u> <u>stage</u> of your recovery.

As before, the information will remain strictly confidential. I enclose a paid reply envelope for return of the forms. I would like to thank you for your participation in this research study -your response has been extremely helpful and is greatly appreciated.

If you have any queries I can be contacted at the University of Leeds School of Healthcare Studies, Department of Applied Health Sciences, telephone number 01943-876151 ext.6223.

With very best wishes,

## APPENDIX V:

# GENERAL HEALTH QUESTIONNAIRE, 28-ITEM VERSION.

# THE GENERAL HEALTH QUESTIONNAIRE GHQ 28 David Goldberg

#### Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

#### Have you recently

A1 – been feeling perfectly well and in good health?	Better	Same	Worse	Much worse
	than usual	as usual	than usual	than usual
A2 — been feeling in need of a good	Not	No more	Rather more	Much more
tonic?	at all	than usual	than usual	than usual
A3 — been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 — felt that you are ill?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
45 — been getting any pains in	Not	No more	Rather more	Much more
your head?	at all	than usual	than usual	than usual
<b>A6</b> — been getting a feeling of tightness	Not	No more	Rather more	Much more
or pressure in your head?	at all	than usual	than usual	than usual
47 — been having hot or cold spells?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
31 – lost much sleep over worry?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
32 — had difficulty in staying asleep	Not	No more	Rather more	Much more
once you are off?	at all	than usual	than usual	than usual
33 — felt constantly under strain?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
34 – been getting edgy and bad-tempered?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
35 – been getting scared or panicky	Not	No more	Rather more	Much more
for no good reason?	at all	than usual	than usual	than usual
<pre>16 — found everything getting on</pre>	Not	No more	Rather more	Much more
top of you?	at all	than usual	than usual	than usual
17 — been feeling nervous and strung-up all the time?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual

#### Have you recently

C1 – been managing to keep yourself	More so	Same	Rather less	Much less
busy and occupied?	than usual	as usual	than usual	than usual
C2 – been taking longer over the things	Quicker	Same	Longer	Much longer
you do?	than usual	as usual	than usual	than usual
C3 – felt on the whole you were doing things well?	Better	About	Less well	Much
	than usual	the same	than usual	less well
C4 – been satisfied with the way	More	About same	Less satisfied	Much less
you've carried out your task?	satisfied	as usual	than usual	satisfied
C5 — felt that you are playing a useful	More so	Same	Less useful	Much less
part in things?	than usual	as usual	than usual	useful
C6 – felt capable of making decisions	More so	Same	Less so	Much less
about things?	than usual	as usual	than usual	capable.
C7 — been able to enjoy your normal	More so	Same	Less so	Much less
day-to-day activities?	than usual	as usual	than usual	than usual
D1 – been thinking of yourself as a	Not	No more	Rather more	Much more
worthless person?	at all	than usual	than usual	than usual
D2 – felt that life is entirely hopeless?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
D3 – felt that life isn't worth living?	Not	No more	Rather more	Much more
	at all	than usual	than usual	than usual
D4 – thought of the possibility that you	Definitely	l don't	Has crossed	Definitely
might make away with yourself?	not	think so	my mind	have
D5 – found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6 – found yourself wishing you were	Not	No more	Rather more	Much more
dead and away from it all?	at all	than usual	than usual	than usual
D7 – found that the idea of taking your	Definitely	l don't	Has crossed	Definitely
own life kept coming into your mind?	not	think so	my mind	has
A B C	D		TOTAL	

C D. Goldberg & The Institute of Psychiatry, 1981

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## APPENDIX VI:

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## ROSENBERG SELF-ESTEEM SCALE

When you think about your own life, how do you feel about the following statements? (1) Strongly agree (2) Agree (3) Disagree (4) Strongly disagree.

	strongly agree	agree	disagree	strong disagr	
I have little control over things that happen to me.	1 .	2		3	4
Sometimes I feel I am being pushed around in life.	1	2		3	4
I often feel helpless in dealing with the problems in life.	1	2		3	4
There is really no way I can solve some of the problems I have.	1	2	:	3	4
There is little I can do to change many of the important things in my life.	1	2	3	3	4
What happens to me in the future mostly depends on me.	1	2	3	3	4
I can do almost anything I set my mind to.	1	2	3	3	4
I feel that I'm a person of wor at least on an equal basis wit others.		2	3	3	4
I feel I have a number of good qualities.	1	2	. 3	3	4
I am able to do things as well as other people.	1	2	2	3	4
All in all I'm inclined to fee that I am a failure.	1 1	2	:	3	4
I feel I don't have much to be proud of.	1	2		3	4
I wish I could have more respect for myself.	ct 1	2	-	3	4
I certainly feel useless at time	mes. 1	2	:	3	4
I take a positive attitude towards myself.	1	2	:	3	4
At times I think I am no good at all.	1	2	• :	3	4
On the whole I am satisfied with myself.	1	2	:	3	4

## APPENDIX VII:

## IMPACT OF EVENT SCALE AND CONSENT FROM AUTHOR

<u>Ouestionnaire ID.</u>

Directions. Below is a list of comments made by people about stressful life events and details related to them. Read each item and decide how frequently each item was true for you DURING THE PAST SEVEN DAYS, regarding your recent time in the Intensive Care Unit at St James's Hospital. If the item did not occur at all in the past seven days, choose the NOT AT ALL option. Otherwise circle the number of the response which best describes that item. Please complete each item.

I CEM.				
(1) Not at all (2) Rarely	(3) So	ometimes	(4) C	ften
	not at all	rarely som	etimes of	ten
<ol> <li>I thought about it when I didn't mean to.</li> </ol>	1	2	3	4
<ol> <li>I avoided letting myself get upset when I thought about it or was reminded of it.</li> </ol>		. 2	3	4
3. I tried to remove it from memory.	1	2	3	4
<ol> <li>I had trouble falling asleep or staying asleep, because of pictures or thoughts that car into my mind.</li> </ol>	E	2	3	4
5. I had waves of strong feeling about it.	gs 1	2	3	4
6. I had dreams about it.	1	2	3	4
<ol> <li>I stayed away from reminders about it.</li> </ol>	1	2	3	4
<ol> <li>I felt as if it hadn't happen or wasn't real.</li> </ol>	ned 1	2	3	4
9. I tried not to talk about it.	. 1	2	3	4
10.Pictures about it popped into my mind.	o 1	2	3	4
11.0ther things kept making me think about it.	1	2	3	4
12.I was aware that I still had a lot of feelings about it, b I didn't deal with them.	1 out	2	3	4
13.I tried not to think about it	. 1	2	3	4
14.Any reminder brought back feelings about it.	1	2	3	4
15.My feelings about it were fairly numb.	1	2	3	4

28 Foxhill Crescent Weetwood Leeds LS16 5PD United Kingdom

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20th April 1994

rang Horors

Dr M. Horowitz M.D. University of California Dept of Psychiatry 401 Parnassus Ave BOX 0984 San Francisco CA 94143-0984 U.S.A.

Dear Dr Horowitz

Thankyou very much for sending the copy of your tests / Packet One.

I am undertaking research for a PhD into the longterm psychological effects of admission to an Intensive Care Unit during critical illness. The proposal is registered at the Metropolitan University here in Leeds.

I would like to use your Impact of Events scale, in conjunction with the General Health Questionnaire, to assess patients' reactions to this stressful life event. May I have your permission to use the scale in my research study?

Thankyou for your help,

Yours sincerely,

Pennij.

# APPENDIX VIII:

## LIFE EVENTS FORM

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#### LIFE EVENTS DURING THE RESEARCH PERIOD.

It is important that any other major happenings in your life are noted which might have had some bearing on your emotional recovery.

During the last twelve months - the period you have been involved in this study - have you experienced any <u>other</u> major events, apart from your illness, which you felt have put an extra strain on you? You need not give details of the event if you do 1 c wish to, but please complete the statement below - Thankyou.

Examples of major events would be:-

The death of a close relative or friend

Divorce or separation

Retirement from work

Losing your job

Legal problems

Do you feel that you have experienced extra strain during this year as a result of some major life event?

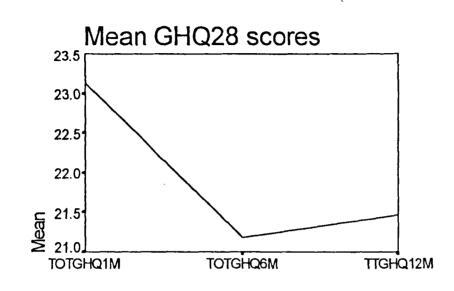
Yes / No

## APPENDIX IX:

GENERAL SCORE PATTERNS (1) GENERAL HEALTH QUESTIONNAIRE (2) SELF-ESTEEM SCALE (3) IMPACT OF EVENT SCALE

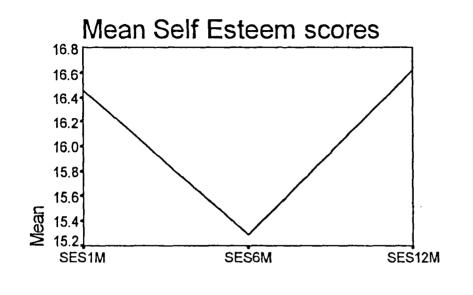
### **APPENDIX IX: GENERAL SCORE PATTERNS**

1:Pattern of GHQ28 scores across follow up period.



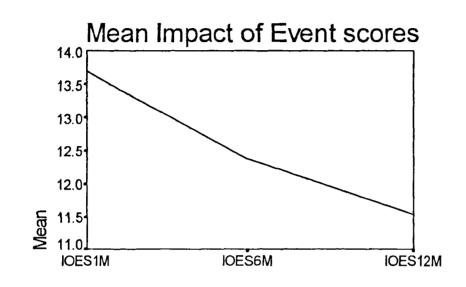
n = 37

TOTGHQ1M = GHQ28 total score at 6 weeks TOTGHQ6M = GHQ28 total score at 6 months TOTGHQ12M = GHQ28 total score at 12 months



n = 37

SES1M = total self esteem score at 6 weeks SES6M = total self esteem score at 6 months SES12M = total self esteem score at 12 months



n = 37

IOES1M = total Impact of Event score at 6 weeks IOES6M = total Impact of Event score at 6 months IOES12M = total Impact of Event score at 12 months

## APPENDIX X:

PATIENTS WHO DIED DURING FOLLOW-UP: CASE MIX.

## APPENDIX X

## Patients who died during follow-up: case mix.

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Age group	18-30 years	2	
	44-56 years	4	
	57-69 years	1	
ICU stay	2-5 days	3	
	6-9 days	2	
	10-13days	2	
Hospital stay	< 25 days	1	
	26-50 days	3	
	51-75 days	2	
	76-100 days	1	
<b></b>	11.00		
Admission severity	11-20	4	
	21-30	2	
	31-40	1	
Recall	None	4	
	Vague	2	
	Full	1	
Communication	Poor	. 6	
	Good	1	
Social support	Lives with next o	f kin	6

Next of kin nearby

1

Sleep	Poor	3
	Reasonable	4

Occupational class	Managerial/technical	2
	Clerical/minor supervisory	3
	Semiskilled manual	2

Mode of admission	Elective	3
	Unconscious from ward	2
	Unconscious from A&E	2
Indication for admission	Cardiovascular	1
	Trauma	1
	Metabolic/endocrine	2
	Transplant	1
	Planned surgery	2
Sex	Male	5
	Female	2
Relatives resident	Yes	1
	No	6
Muscle relaxants	No	7
Cancer	Yes	3
	No	4

# APPENDIX XI:

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SUBGROUP STATISTICS

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Mean, median, standard deviation of outcome scores by Age groups.

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Report

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		TOTGHQ1	TOTGHQ6	TTGHQ12						
age reduced to groups	8	M	M	Σ	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
1.00	Mean	28.0000	33.4286	30.6667	20.6250	20.2857	19.6667	21.3750	19.0000	17.3333
	Median	24.5000	31.0000	33.5000	20.5000	21.0000	20,0000	24.5000	23.0000	17.5000
	Std. Deviation	19.3465	20.0571	20.7139	7.5581	4.9570	6.1860	10.8620	12.6886	14.5556
	N	8	7	9	Ø	7	Q	œ	~	ç
2.00	Mean	26.4286	19.1429	22.2857	19.0000	16.2857	17.7143	13.7143	8.5714	15.2857
	Median	24.0000	14.0000	22.0000	20.0000	17.0000	16.0000	15.0000	3.0000	8.0000
	Std. Deviation	10.8912	15.5716	7.4098	7.6594	3.8607	7.2276	11.6149	10.3418	15.2612
	N	7 '	~	~	7	~	~	~	~	~
3.00	Mean	22.5000	20.9545	19.9000	16.3333	14.3636	15.9500	12.5417	12.2273	10.4000
	Median	21.5000	16.5000	14.0000	16.5000	14.0000	14.0000	12.0000	12.0000	8.5000
	Std. Deviation	13.4196	15.2455	14.8427	8.9863	8.7752	9.0523	9.3296	9.6704	10.8502
	Z	24	ន	20	24	8	20	24	ន	2
4.00	. Mean	26.4000	22.6000	14.0000	12.4000	14.2000	13.5000	7,0000	5.2000	2.0000
	Median	22.0000	24.0000	11.0000	15.0000	17.0000	14.5000	6.0000	5.0000	1.5000
	Std. Deviation	15.7258	12.8957	9.0185	8.1731	7.9183	10.3441	5.5678	5.8052	2,1602
	z	S	S	4	ŝ	ŝ	4	10	IJ	4
Totai	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000 9	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.6909	8.3245	10.2176	10.4446	12.2443
	z	44	4	37	44	41	37	4	4	37

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÷

		GHQDEP	GHQDEP	GHQDE12
		1M	6M	Σ
Mean		3.88	00'1	6.17
Median		1.00	8.00	8.00
Std Deviation	ation	4.88	6.43	4.96
Valid N		N=8	N=7	N=6
Mean		1.29	1.71	2.43
Median		8	8.	1.00
Std Deviation	ation	2.21	4.11	2.88
Valid N		N=7	N=7	N=7
Mean		1.50	1.95	2.70
Median		8	8	<u>8</u>
Std Deviation	iation	3.60	4.08	4.78
Valid N		N=24	N=22	N=20
Mean		1.00	.80	.25
Median		8.	8 <sup>.</sup>	<u>8</u>
Std Deviation	ation	1.73	1.30	.50
Valid N		N=5	N=5	N=4

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minean, inequan, standard deviation of outcome scores by ICU stay.

			TOTGHQ1 TOTGHQ6		TTGHQ12	SES1M	SFS6M	SFS12M	IOES1M	IOES6M	IOES12M
NEWICSTY 1.00	1.00	Mean	24.94	23.21	24.85	17.32	17.24	18.41	12.42	12.00	11.56
		Median	23.00	19.00	22.00	18.00	18.00	17.00	12.00	12.00	8.00
		Std Deviation	13.75	15.11	15.27	7.39	7.30	8.19	10.49	10.65	12.01
		Valid N	N=31	N=29	N=27	N=31	N=29	N=27	N=31	N=29	N=27
	2.00	Mean	23.69	22.42	12.30	16.54	11.92	11.80	16.77	11.67	11.50
		Median	22.00	15.50	9.50	15.00	12.00	12.00	19.00	8.50	6.00
		Std Deviation	15.85	19.01	7.30	11.11	7.20	6.94	9.20	10.40	13.53
		Valid N	N=13	N=12	N=10	N=13	N=12	N=10	N=13	N=12	N=10

Mean, median, standard deviation of outcome scores by Sleep.

			TOTGHQ1 TOT	TOTGHO6	TTGHQ12						
			Σ	Σ	Σ	SES1M	SES6M	SES12M	IOES1M	IOES6M	10ES12M
Sleep	p 1.00	Mean	23.00	24.53	21.88	17.60	16.21	17.06	15.15	13.53	15.41
5		Median	21.50	16.00	19.00	18.50	17.00	16.00	14.50	14.00	15.00
20		Std Deviation	13.00	19.22	14.51	7.18	5.98	7.48	9.20	10.21	12.81
_		Valid N	N=20	N=19	N=17	N=20	N=19	N=17	N=20	N=19	N=17
	2.00	Mean	25.88	21.64	21.10	16.67	15.23	16.25	12.50	10.50	8.25
		Median	24.50	22.50	15.50	16.00	17.00	15.00	11.00	7.00	3.50
		Std Deviation	15.32	13.17	15.07	9.64	8.87	9.16	11.05	10.68	11.00
		Valid N	N=24	N=22	N=20	N=24	N=22	N=20	N=24	N=22	N=20

Mean, median, standard deviation of outcome scores by Hospital stay groups.

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Report

grouped length		TOTGHQ1	TOTGHQ6	TTGHQ12						
of stay sjuh		Σ	¥	W	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
1.00	Mean	26.8750	23.1250	23.8667	17.8750	18.3125	18.2667	13.8750	11.2500	10.0000
	Median	22.0000	16.5000	19.0000	19.5000	20.0000	17.0000	11.5000	5.5000	5.0000
	Std. Deviation	15.6966	16.1941	17.2952	7.3292	7.6395	9.4903	11.4593	12.3477	11.5202
	Z	16	16	15	16	16	15	16	16	15
2.00	Mean	24.4545	23.7500	19.5789	17.0909	13.5500	15.3158	14.0000	11.6500	13.1053
	Median	24.0000	18.0000	18.0000	16.5000	13.5000	15.0000	14.0000	8.5000	9.0000
	Std. Deviation	14.3584	17.9088	12.0891	9.9900	7.7015	7.8035	9.3808	9.2411	13.5642
	z	8	20	19	ន	20	19	22	20	19
3.00	Mean	23.7500	21.2500	28.0000	17.0000	16.7500	17.5000	16.7500	15.7500	5.0000
	Median	23.0000	25.0000	28.0000	19.5000	19.0000	17.5000	21.0000	19.0000	5.0000
	Std. Deviation	4.8563	8.1803	21.2132	6.7823	5.2520	7.7782	11.3248	11.3541	4.2426
	Z		4	2	4	4	2	4	4	8
4.00	Mean	5.0000			12.0000			0000.		
	Median	5.0000		^.	12.0000			0000		
	Std. Deviation	•				-		•		
	z	-			-			-		
5.00	Mean	13.0000	12.0000	8.0000	10.0000	12.0000	15.0000	6.0000	12.0000	18.0000
	Median	13.0000	12.0000	8.0000	10.0000	12.0000	15.0000	6.0000	12.0000	18.0000
-	Std. Deviation	•	•	•	•		•	•	•	•
	Z	*	-	*-	*	-	~	**	-	-
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	4	4	37	44	41	37	44	4	37

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Mean, median, standard deviation of outcome scores by Admission severity groups.

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		TOTGHQ1	TOTGHQ6	TTGHQ12						
GPSEVRTY		Μ	¥	ž	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
1.00	Mean	28.8571	25.7143	28.7143	20.2857	20.1429	21.1429	10.5714	8.0000	11.7143
	Median	22.0000	24.0000	24.0000	20.0000	18.0000	25.0000	4.0000	2.0000	8.0000
	Std. Deviation	16.7872	17.9510	18.1816	4.8892	5.3050	7.8831	11.4289	10.6615	11.9960
	z	7	7	7	~	~	~	7	7	7
2.00	Mean	26.3000	26.8947	25.1875	19.3500	18.6842	19.3750	14.7000	14.8421	12.4375
	Median	24.0000	25.0000	. 22.0000	20.0000	19.0000	18.5000	14.5000	15.0000	9.0000
	Std. Deviation	15.5533	17.3041	15.0431	7.2929	5.3960	7.5000	10.8098	10.6940	12.1763
	N	20	19	16	8	19	16	20	19	16
3.00	Mean	20.9167	16.6364	14.3000	12.6667	9.3636	11.3000	13.6667	9.9091	11.0000
	Median	19.0000	14.0000	12.0000	9.0000	11.0000	14.0000	12.0000	7.0000	3.5000
	Std. Deviation	11.8126	13.3811	9.0314	11.6411	8.1274	7.6746	10.8906	9.9845	14.6287
	z	12	.11	10	12	11	10	42	11	. 10
<b>4</b> .00	Mean	20.4000	17.0000	11.7500	14.2000	11.0000	11.0000	14.2000	10.2500	9.0000
	Median	22.0000	15.0000	9.5000	15.0000	11.5000	11.0000	14.0000	8.5000	6.0000
	Std. Deviation	10.5262	10.4881	5.6789	2.7749	6.1644	4.9666	4.7645	10.0125	10.6771
	z	5	4	4	5	4	4	ŝ	4	4
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	44	41	37	44	41	37	44	4	37

Mean, median, standard deviation of outcome scores by Recall

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Report

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baueur lecal	-		1 101GH06	11GH012						
of time on icu		X	Σ	W	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
no recal	Mean	26.5385	24.6667	25.7778	20.4615	17.4167	18.5556	17.3846	13.2500	14.3333
	Median	23.0000	21.0000	22.0000	20.0000	19.0000	22.0000	23.0000	10.5000	9.0000
	Std. Deviation	14.6493	18.0571	16.4452	8.8187	7.4646	8.7623	11.9481	12.7431	14.3527
	z	13	12	6	13	12	o	13	42	6
vague recali	Mean	222.7917	21.6522	18.4091	15.2917	14.7391	15.7727	11.8750	11.5217	10.2273
	Median	22.0000	19.0000	13.0000	15.5000	15.0000	15.0000	10.5000	8.0000	3.5000
	Std. Deviation	12.5766	. 15.0321	12.4963	8.1320	7.3002	7.5652	9.3218	9.7135	12.4362
	Z	24	23	22	24	23	22	24	23	8
high recall	Mean	27.0000	24.6667	26.1667	17.0000	15.8333	16.8333	13.1429	10.6667	12.1667
	Median	28.0000	20.5000	23.0000	17.0000	17.0000	16.5000	16.0000	10.5000	13,5000
	Std. Deviation	19.6638	18.5652	18.6592	8.6217	9.6212	11.2146	9.2993	9.6678	8.8412
	Z	2	9	9	7	Q	G	~	9	9
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	44	41	37	4	41	37	44	41	37

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Mean, median, standard deviation of outcome scores by Communication.

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Report

patient ability to		TOTGHQ1	TOTGHQ6	TTGHQ12						
communicate		W	W	Σ	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
poor	Mean	22.4194	22.4828	21.1600	16.7097	14.9310	15.6800	13.5806	11.6207	9.9200
•	Median	21.0000	17.0000	17.0000	16.0000	17.0000	15.0000	14.0000	. 8.0000	3.0000
	Std. Deviation	13.9207	16.3327	15.3750	8.9450	7.6295	8.3052	10.5349	10.7018	12.0759
	N	31	29	. 25	31	29	25	3	29	25
Bood	Mean	29.6923	24.1667	22.0833	18.0000	17.5000	18.5833	14.0000	12.5833	14.9167
	Median	27.0000	19.0000	21.0000	18.0000	17.5000	16.0000	12.0000	13.0000	16.0000
	Std. Deviation	14.1503	16.1799	13.5140	7.6920	7.5015	8.3716	9.8234	10.2199	12.4130
	Z	13	12	12	13	4	12	13	12	12
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17,0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	44	41	37	44	41	37	4	41	37

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Mean, median, standard deviation of outcome scores by Social support.

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Report

social support anticipated		TOTGHQ1 M	TOTGHQ6	TTGHQ12	CCC1M	Maccem	CEC40M	ICER I	. Nacato	ICE642M
lives with	Mean	25.6667	22.5000	20.4074	17.2727	15.3000	16.0370	13.8788	11.5333	10.7407
friend/partner/next of kin	Median	24.0000	18.0000	15.0000	18.0000	16.0000	15.0000	12.0000	10.0000	8.0000
	Std. Deviation	14.5895	15.9043	14.1564	9.0770	7.8527	9.1797	10.3524	10.5004	11.6474
	Z	33	30	27	33	0e S	27	33	30	27
lives alone next of kin	Mean	21.8889	25.4444	23.8750	17.6667	17.2222	18.7500	12.4444	12.7778	12.8750
nearby	Median	16.0000	27.0000	20.5000	21.0000	19.0000	16.5000	14.0000	9.0000	7.0000
	Std. Deviation	14.4520	19.1580	18.0826	6.9101	7.6121	6.0415	10.8641	11.6702	14.0757
	z	6	6	Ø	0	თ	80	0	<b>0</b> 7	60
lives alone no social	Mean	18.5000	19.0000	26.0000	11.5000	14.5000	16.0000	16.5000	13.5000	17.0000
support	Median	18.5000	19.0000	26.0000	11.5000	14.5000	16.0000	16.5000	13.5000	17.0000
	Std. Deviation	6.3640	2.8284	8.4853	6.3640	4.9497	1.4142	9.1924	7.7782	19.7990
	N	2	2	0	2	2	2	2	8	2
R Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z.	44	41	37	44	41	37	44	4	37

Mean, median, standard deviation of outcome scores by Occupational class. Report

8.6000 2.0000 8.5556 2.0000 11.5338 17.0000 14.4684 9.0000 9.0000 12.7279 11.5405 12.2443 8.5000 8.0000 5.8797 17.0000 8.0000 4.3108 OES12M 10.4446 11.0770 11.0909 18.5000 14.5000 3.0000 5.0000 9.0000 14.5000 20.5061 11.9024 9.2000 7.5664 9.2461 15.8571 4 9.0000 7.6667 11.4412 OES6M 6.9642 11.9000 10.5000 9.6084 20.0000 20.0000 12.7279 13.7045 10.2176 11.5000 9.0988 23.0000 11.9072 13.0000 12.0000 14.0000 12 5 10.6667 12 17.0667 4 **OES1M** 14.0000 22.0000 6.4609 15.5000 2.1213 8.3245 37 11.4324 7.4150 13.0000 9.1924 15.5000 16.6216 15.0000 16.0000 ю 14.1250 <del>2</del> 13.6667 14.8000 21.0769 SES12M 14.0000 7.4162 5 13.2222 5.9535 1.4142 17.0000 12.8182 12.0000 19.2143 21.5000 22.0000 7.5909 41 7.2224 8.1541 17.0000 4 22.0000 F 15.6829 SES6M 9.0000 6.2103 15.0000 16.0000 17.5000 12.7500 12.5000 8.1755 18.5000 17.5000 10.4051 22.0000 8.5258 4 20.8667 18.5000 17.4000 9 .7071 17.0909 4 SES1M 26.8000 22.0000 19.9675 17.0000 12.6689 6.3231 11.0000 18.0000 14.6147 18.3750 Ø 20.0000 18.0000 18.0000 TIGHQ12 24.4615 18.1871 ę 8.4853 37 17.6667 21.4595 TOTGHQ6 M 25.8000 19.0000 22.8626 22.4444 17.0000 18.0008 18.8182 17.0000 10.5624 24.9286 21.0000 27.5000 27.5000 19.0000 17.7654 12.0208 22.9756 16.1036 Ŧ 4 4 24.0000 24.9000 23.0000 13.9479 20.0000 22.0000 13.0245 25.0000 17.7179 23.0000 24.5682 22.5000 14.2248 23.0000 1.4142 4.8477 2 TOTGHO1 22.0000 29.0667 4 Std. Deviation Std. Deviation Std. Deviation Std. Deviation Std. Deviation Std. Deviation Median Median Median Median Median Median Mean Mean Mean Mean Mean Mean z z z Z Z z Managerial/ technical class by occupation Professional Semi-skilled manual Clerical /minor supervisory Student Total

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-mean, meanan, standard tevration of outcome scores by mode of admission.

			TOTGHQ1	TOTGHQ6	TTGHQ12						
			Σ	V	ž	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
	1.00	Mean	21.70	19.45	21.75	16.04	15.86	18.15	9.26	10.18	10.70
		Median	22.00	16.50	19.50	17.00	17.50	16.00	4.00	7.50	6.50
		Std Deviation	11.57	13.36	13.01	7.51	6.99	8.09	9.43	9.54	11.40
		Valid N	N=23	N=22	N=20	N=23	N=22	N=20	N=23	N=22	N=20
0	2.00	Mean	40.33	33.33	39.33	22.00	22.33	22.00	21.67	16.33	18.33
		Median	31.00	31.00	49.00	25.00	25.00	25.00	25.00	17.00	17.00
		Std Deviation	21.57	23.59	24.95	7.94	7.37	7.94	8.50	12.01	15.04
		Valid N	N=3	E=N	S=S	N≡3	N=3	N=3	E=N	E=N	N=3
r,	3.00	Mean .	27.50	26.42	18.70	18.86	14.75	14.20	19.29	13.75	9.30
		Median	24.50	23.00	16.50	17.50	15.00	13.50	21.00	10.00	3.00
		Std Deviation	. 15.90	17.58	13.68	9.94	8.20	7.25	9.10	12.12	11.80
		Valid N	N=14	N=12	N=10	N=14	N=12	N=10	N=14	N=12	N=10
4	400	Mean	19.00	24.25	13.50	13.25	12.50	11.00	13.75	12.50	16.25
		Median	20.50	18.00	10.00	15.50	13.00	9.50	11.50	11.50	12.00
		Std Deviation	10.92	21.36	9.26	9.57	9.04	10.55	8.81	11.27	17.61
		Valid N	N=4	N=4	N=4	N=4	N=4	N=4	N=4	N≖4	N=4

### <u>יייישיוי, יויכשוון, סנמושמוע עכעומנוטון טו ועבס ווונועטוטו צעמצכמופ טע צופפן.</u>

INTRU12M	8.18	6.00	7.09	N=17	4.60	1.50	6.00	N=20
INTRUSIM INTRUGM INTRUIZM	7.17	6.00	6.21	N=18	5.00	4.00	5.23	N=22
INTRUS1M	02'2	7.00	5.97	N=20	5.21	3.50	5.32	N=24
	Mean	Median	Std Deviation	Valid N	Mean	Median	Std Deviation	Valid N
	1.00				2.00			
	Sleep	5 2	3					

## Mean, median, standard deviation of IOES avoidance subscale by Mode of admission.

			AVOID1M	AVOIDEM	VOID12M
Node of	1.00	Mean	4.52	5.45	4.55
admission		Median	3.00	3.50	1.50
		Std Deviation	4.80	5.53	5.74
		Valid N	N=23	N=22	N=20
	2.00	Mean	12.67	7.33	7.67
		Median	13.00	9.00	9.00
		Std Deviation	.58	6.66	7.09
		Valid N	N=3	N≡3	N=3
	3.00	Mean	11.29	7.91	5.20
		Median	10.00	7.00	1.50
		Std Deviation	5.57	6.33	6.53
		Valid N	N=14	N=11	N=10
	4.00	Mean	6.00	3.75	7.50
		Median	4.00	4.00	4.00
		Std Deviation	5.48	3.30	9.98
		Valid N	N=4	N=4	N=4

Mean, median, standard deviation of outcome scores by Indication for admission.

Report

		TOTGHO1	TOTGHO6	TTGH012						
Indication for admission		¥	¥	M	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
Respiratory	Mean	19.0000	23.1429	20.7143	15.2857	15.4286	16.2857	17.5714	15.4286	14.4286
•	Median	16.0000	17.0000	15.0000	13.0000	14.0000	13.0000	14.0000	12.0000	0000.6
	Std. Deviation	8.8882	15.5395	14.0797	9.1417	9.2890	8.1182	10.2283	12.0535	16.4404
•	Z	7	7	7	~	~	~	~	7	7
Cardiovascular	Mean	32.0000			17.0000			19.0000		
	Median	32.0000			17.0000			19.0000		
	Std. Devlation	•			•			•		
	z	*			-			-		_
Trauma	Mean	45.5000	45.2500	38.0000	24.2500	20.7500	22.3333	26.7500	19.5000	22.3333
	Median	55.5000	54.5000	53.0000	27.0000	21.5000	27.0000	25.5000	20.0000	17.0000
	Std. Deviation	26.8639	26.8747	30.4138	9.9457	7.5443	8.9629	4.3493	11.7047	9.2376
	z	4	4	3	4	4	e	4	4	ŋ
Metab/endoc	Mean	23.2500	18.3333	14.0000	19.7500	13.6667	11.0000	17.5000	11.0000	1.5000
	Median	24.5000	21.0000	14.0000	18.0000	18.0000	11.0000	17.5000	8,0000	1.5000
-	Std. Deviation	6.9940	8.3267	8.4853	9.7425	9.2916	8.4853	9.2556	12.7671	2.1213
	z	4	3	2	4	ຕ	2	4	e	2
Transplant	Mean	18.3571	20.4615	21.7692	14.7857	13.3077	16.3846	9.6429	10.8462	9.6154
-7-	Median	22.0000	17.0000	17.0000	15.5000	14.0000	15.0000	7.5000	12.0000	2.0000
	Std. Deviation	7.8702	15.0699	15.1281	7.6075	7.1808	7.5888	8.8196	8.1634	12.2579
	z	14	13	13	14	13	13	14	13	13
Plan.surgery	Mean	27.1000	19.0000	20.5000	18.0000	19.0000	19.6250	8.7000	9.7000	13.0000
	Median	22.5000	16.5000	19.5000	19.0000	19.0000	16.5000	4.0000	3.5000	9.0000
	Std. Deviation	13.9320	10.9545	8.8641	6.9282	5.0332	9.3951	10.2095	11.1460	9.4718
	Z	10	10	8	10	10	8	10	10	8
Unplan.surgery	Mean	28.2500	22.0000	15.0000	16.2500	12.0000	10.5000	15.5000	7.7500	6.7500
	Median	25,0000	22.0000	14.5000	16.5000	12.0000	12.5000	15.0000	3.5000	1.5000
	Std. Deviation	14.9750	13.1656	7.5277	13.1244	9.0185	7.5939	8.8129	11.3248	11.5866
	Z	4	4	4	4	4	4	4	4	4
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	. 15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	44	41	37	44	41	37	44	41	37

# wean, median, standard deviation of GHQ depression subscale by Indication for admission.

			GHQDEP 1M	GHQDEP 6M	GHQDE12 M
Indication	Respiratory	Mean	1.14	3.14	2.57
Tor Definition		Median	8.	0.	8
		Std Deviation	3.02	4.56	4.16
		Valid N	N=7	N=7	N=7
	Cardiovascular	Mean	1.00	•	•
		Median	1.00	•	•
		Std Deviation	•	•	•
		Valid N	N=1	0=N	0=0
	Trauma	Mean	9.50	11.50	9 <sup>.00</sup>
		Median	10.50	13.50	10.00
		Std Deviation	6.24	7.85	8.54
		Valid N	N=4	N=4	N=3
	Metab/endoc	Mean	1.50	.33	8.
		Median	1.50	<u>8</u>	8
,		Std Deviation	1.73	.58	8
		Valid N	N=4	N=3	N=2
	Transplant	Mean	.43	69	3.00
		Median	8.	<u>8</u>	8
		Std Deviation	1.09	1.70	4.30
-		Valid N	N=14	N=13	N=13
	Plan.surgery	Mean	1.70	1.90	2.13
		Median	8.	1.00	.50
		Std Deviation	2.67	2.77	2.90
		Valid N	N=10	N=10	N=8
	Unplan.surgery	Mean	1.25	2.75	2.00
		Median	8	.50	.50
		Std Deviation	2.50	4.86	3.37
		Valid N	N=4	N=4	N=4

wreart, metually standard deviation of IUES avoidance subscale by Indication for admission.

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				AVOID1M	AVOIDEM	VOID12M
	Indication	Respiratory	Mean	10.00	6.14	6.43
	Tor		Median	12.00	7.00	2.00
			Std Deviation	5.42	5.81	8.60
			Valid N	N=7	N=7	N=7
		Cardiovascular	Mean	7.00	•	•
			Median	7.00	-	•
	_		Std Deviation	•	-	•
			Valid N	N=1	N=0	N=0
		Trauma	Mean	13.75	11.67	11.67
			Median	12.50	12.00	12.00
			Std Deviation	4.35	2.52	2.52
			Valid N	N=4	£≡N	. €=N
		Metab/endoc	Mean	11.00	6.00	<u>8</u>
			Median	10.50	4.00	8 <sub>.</sub>
			Std Deviation	5.35	7.21	8
	_		Valid N	N=4	£≡N	N=2
)		Transplant	Mean	4.29	5.23	4.23
λ			Median	3.00	6.00	1.00
ŧ			Std Deviation	4.20	4.25	5.70
			Valid N	N=14	N=13	N=13
		Plan.surgery	Mean	4.70	5.80	5.25
			Median	1.50	2.50	3.50
			Std Deviation	5.58	6.86	5.78
			Valid N	N=10	N=10	N=8
		Unplan.surgery	Mean	10.25	5.50	4.75
			Median	9.50	3.00	1.50
			Std Deviation	7.41	7.55	7.63
			Valid N	N=4	N=4	N=4

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Mean, median, standard deviation of outcome scores by Sex.

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Report

		TOTGHQ1	TOTGHQ6	TTGHQ12						
Sex		W	M	×	SES1M	SESGM	SES12M	IOES1M	IOES6M	IOES12M
Male	Mean	24.3667	23.2500	22.9200	17.0000	15.7500	16.4000	14.9000	11.3929	11.1600
	Median	22,5000	18.0000	20.0000	18.0000	17.0000	16.0000	13.5000	10.0000	8.0000
	Std. Deviation	13.8078	16.3450	15.0525	8.9597	7.9425	8.7607	10.1484	10.8742	12.2837
	Z	30	28	25	30	28	25	30	28	25
Female	Mean	25.0000	22.3846	18.4167	17.2857	15.5385	17.0833	11.1429	13.0000	12.3333
_	Median	23.0000	19.0000	12.5000	15.0000	17.0000	14.5000	9.0000	9.0000	7.0000
_	Std. Deviation	15.6106	16.2098	13.7739	7.8292	7.0783	7.6807	10.2571	9.7809	12.6659
	z	14	13	12	14	13	12	14	13	42
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	Z	· 44	41	37	44	41.	37	44	. 41	37

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. ţ Mean, median, standard deviation of outcome scores by Relatives residence on ICU

Report

relative resident		TOTGHQ1	TOTGHQ6	TTGHQ12						
while patient on icu		Σ	Z	Σ	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
relatives resident	Mean	25.2857	24.4286	15.1667	17.5714	14.7143	12.0000	15.8571	12.7143	9.1667
	Median	24.0000	19.0000	10.5000	19.0000	17.0000	13.5000	14.0000	14.0000	8.5000
	Std. Deviation	16.2349	19.6880	13.7901	10.3095	6.8243	7.7974	9.5469	9.0869	8.6814
	z	~	7	G	7	7	G	~	~	0
relatives not resident	Mean	24.4324	22.6765	22.6774	17.0000	15.8824	17.5161	13.2973	11.7353	12.0000
	Median	22.0000	18.0000	20.0000	17.0000	17.0000	16.0000	12.0000	8.0000	8.0000
	Std. Deviation	14.0585	15.5986	14.6683	8.3100	7.8190	8.2416	10.4133	10.8189	12.8841
	z	37	34	31	37	34	31	37	8	31
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22,5000	19,0000	18.0000	17.5000	17.0000	15.0000	13.0000	9.0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	N	44	41	37	44	41	37	4	41	37

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Mean, median, standard deviation of outcome scores by Muscle relaxant (paralysing) drugs.

Report

paralysing agent		TOTGHQ1	TOTGHQ6	TTGHQ12						
administered?		Σ	Σ	Σ	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
no paralysing agents	Mean	24.9512	23.0526	21.8235	17.2683	15.7632	16.9412	13.9756	12.6316	12.4706
	Median	24.0000	· 18.0000	17.5000	18.0000	17.0000	15.0000	14.0000	12.0000	8.5000
	Std. Deviation	14.6372	16.4431	15.0705	8.7636	7.5065	8.4493	10.5392	10.4556	12.3441
	z	4	38	94 14	41	38	æ	41	38	8
paralysing agents	Mean	19.3333	22.0000	17.3333	14.6667	14.6667	13.0000	10.0000	2.6667	1.0000
administered	Median	22.0000	21.0000	20.0000	16.0000	18.0000	17.0000	10.0000	0000.	0000
	Std. Deviation	4.6188	13.5277	8.3267	4.1633	10.4083	6.9282	1.0000	4.6188	1.7321
	N	3	e	e	m	n	n	m	e	e
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	<u>9</u> .0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	4	41	37	44	41	37	44	41	37

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Mean, median, standard deviation of outcome scores by Cancer.

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Report

cancer part of		TOTGHQ1	101	TTGHQ12						
original problem		W	Δ	W	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
Patient has cancer	Mean	26.5385	20.6667	20.1000	18.3077	16.7500	17.5000	8.5385	7.5833	10.3000
	Median	25.0000	21.0000	18.0000	19.0000	17.5000	16.5000	4.0000	2.0000	6.5000
	Std. Deviation	12.2516	10.2366	10.1702	9.3129	7.1874	8.8349	9.7178	9.8761	10.9347
	z	13	12	9	13	12	9	13	12	10
Patient does not	Mean	23.7419	23.9310	21.9630	16.5806	15.2414	16.2963	15.8710	13.6897	12.0000
have cancer	Median	22,0000	19.0000	18.0000	17.0000	15.0000	15.0000	14.0000	12.0000	9.0000
	Std. Devlation	15.0863	18.0573	16.0922	8.2816	7.8315	8.2779	9.7698	10.3064	12.8602
	z	31	59	27	31	29	27	31	29	27
Total	Mean	24.5682	22.9756	21.4595	17.0909	15.6829	16.6216	13.7045	11.9024	11.5405
	Median	22.5000	19.0000	18.0000	17.5000	17.0000	15.0000	13.0000	<b>6</b> .0000	8.0000
	Std. Deviation	14.2248	16.1036	14.6147	8.5258	7.5909	8.3245	10.2176	10.4446	12.2443
	z	4	41	37	4	41	37	44	4	37

Mean, median, standard deviation of outcome scores by Life events.

Report

•		TOTGHQ1	<b>TOTGHQ6</b>	TTGHQ12						
life events in follow up		¥	X	ž	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
significant life events	Mean	22.7500	19.6500	22.0500	18.4000	16.6000	18.9000	13.2500	13.1000	11.1500
occurred	Median	22.0000	16.5000	19.5000	19.5000	17.5000	17.0000	12.5000	14.5000	8.0000
	Std. Deviation	11.2056	13.7047	12.7340	7.6599	6.7153	7.4826	10.4774	10.1146	11.3336
	z	20	20	20	20	20	30	20	8	20
no significant life	Mean	23.5882	23.0000	20.7647	14.1765	13.7647	13.9412	14.2353	11.5294	12.0000
events occurred	Median	22.0000	17.0000	13.0000	15.0000	14.0000	13.0000	12.0000	9.0000	5.0000
	Std. Deviation	15.5365	16.5718	16.9430	8.7410	9.0521	8.6781	9.2637	10.8577	13.5785
	Z	17	17	17	17	17	17	17	17	17
Total	Mean	23.1351	21.1892	21.4595	16.4595	15.2973	16.6216	13.7027	12.3784	11.5405
	Median	22.0000	17.0000	18.0000	17.0000	17,0000	15.0000	12.0000	12.0000	8,0000
	Std. Devlation	13.1807	14.9682	14.6147	8.3353	7.8912	8.3245	9.8146	10.3450	12.2443
	z	37	37	37	37	37	37	37	37	37

### **APPENDIX XII:**

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### SUBGROUP STATISTICS WITH MISSING VALUES TREATED LISTWISE - FOR COMPARISON.

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GHQ statistics: Age, Stay ICU, Hospital stay, Admission severity (12 month survivors)

			TOTGHQ1M			TOTGHQ6M			TTGHQ12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
age reduced	1.00	26.67	24.50	14.96	28.00	28.00	15.34	30.67	33.50	20.71
to groups	<b>5</b> 00	26.43	24.00	10.89	19.14	14.00	15.57	22.29	22.00	7.41
	3.00	21.50	17.50	14.42	20.50	15.50	15.95	19.90	14.00	14.84
	4.00	20.25	18.00	8.81	18.00	18.50	8.98	14.00	11.00	9.02
length of stay	1.00	24.70	22.08	14.13	22.78	19.00	16.21	24.04	22.00	14.84
ICU grouped	2.00	22.00	23.50	6.51	18.67	18.00	8.52	24.33	17.50	17.36
	3.00	17.40	13.00	9.66	24.00	17.00	18.21	13.40	11.00	7.89
	4.00	23.00	14.00	22.87	9.33	8.00	4.16	9.33	7.00	7.77
grouped	1.00	25.27	22.00	14.82	21.93	14.00	16.02	23.87	19.00	17.30
length of stay	2.00	22.11	23.00	12.84	21.53	17.00	15.30	19.58	18.00	12.09
lainu	3.00	22.00	22.00	4.24	17.00	17.00	11.31	28.00	28.00	21.21
	6.00	13.00	13.00		12.00	12.00	•	8.00	8.00	•
GPSEVRTY	1.00	. 28.86	22.00	16.79	25.71	24.00	17.95	28.71	24.00	18.18
	2.00	24.38	24.00	12.59	23.63	20.00	15.25	25.19	22.00	15.04
	3.00	19.40	14.50	12.44	15.80	13.00	13.80	14.30	12.00	9.03
	4.00	17.50	18.00	9.57	17.00	15.00	10.49	11.75	9.50	5.68

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IOES statistics: Age, Stay ICU, Hospital stay, Admission severity (12 month survivors)

			IOES1M			IOES6M			IOES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
age reduced	1.00	24.17	25.50	7.76	21.33	25.50	12.14	17.33	17.50	14.56
to groups	200	13.71	15.00	11.61	8.57	3.00	10.34	15.29	8.00	15.26
	3.00	11.55	11.00	8.73	12.20	12.00	9.32	10.40	8.50	10.85
	4.00	8.75	8.50	4.57	6.50	6.00	5.80	2.00	1.50	2.16
length of stay	1.00	12.74	11.00	10.61	12.57	14.00	10.77	11.30	8.00	11.86
ICU grouped	2.00	15.33	12.00	7.53	11.17	10.00	9.85	9.17	3.50	12.84
	3.00	13.40	14.00	9.69	14.40	12.00	11.10	18.40	18.00	15.57
	4.00	18.33	23.00	10.79	10.00	7.00	11.79	6.67	3.00	9.07
grouped	1.00	14.80	12.00	11.23	12.00	7.00	12.40	10.00	5.00	11.52
length of stay	2.00	12.47	12.00	9.10	12.00	9.00	9.36	13.11	9.00	13.56
sjun	3.00 .00	21.00	21.00	8	19.00	19.00	5.66	5.00	5.00	4.24
	5.00	6.00	6.00	•	12.00	12.00	•	18.00	18.00	•
GPSEVRTY	9.1	10.57	4.00	11.43	8.00	2.00	10.68	11.71	8.00	12.00
	2.00	16.75	15.50	9.58	17.31	18.00	9.74	12.44	9.00	12.18
	3.00	11.30	9.00	10.37	8.40	5.50	9.11	11.00	3.50	14.63
	4.00	13.00	12.00	4.55	10.25	8.50	10.01	00.6	6.00	10.68

SES statistics: Age, Stay ICU, Hospital stay, Admission severity (12 month survivors)

			SES1M			SES6M			SES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
age reduced	1.00	20.00	20.50	5.83	20.83	22.00	5.19	19.67	20.00	6.19
to groups	2.00	19.00	20.00	7.66	16.29	17.00	3.86	17.71	16.00	7.23
	3.00	15.15	14.00	8.98	13.80	13.00	9.02	15.95	14.00	9.02
	4.00	13.25	16.00	9.18	12.75	15.00	8.34	13.50	14.50	10.34
length of stay	1.0	17.91	19.00	7.82	17.17	18.00	7.75	18.61	17.00	8.37
ICU grouped	2.00	15.67	14.50	6.71	14.33	16.00	7.87	15.17	15.00	8.01
	3.00	12.20	13.00	7.66	11.80	12.00	7.79	13.80	12.00	6.91
	<b>4</b> . 8	14.00	10.00	16.37	8.67	12.00	6.66	9.00	12.00	7.94
grouped	1.00	18.47	20.00	7.18	18.20	20.00	7.89	18.27	17.00	9.49
length of stay	8	15.42	16.00	9.24	13.37	13.00	7.87	15.32	15.00	7.80
Infe	а. 00 00 00	14.50	14.50	10.61	13.50	13.50	6.36	17.50	17.50	7.78
	5.00	10.00	10.00	•	12.00	12.00	•	15.00	15.00	-
GPSEVRTY	1.00	20.29	20.00	4.89	20.14	18.00	5.30	21.14	25.00	7.88
	2.00	19.63	21.00	6.64	18.63	18.50	5.88	19.38	18.50	7.50
	3.00	9.90	7.50	10.26	8.30	9.50	7.72	11.30	14.00	7.67
	4.00	13.50	14.00	2.65	11.00	11.50	6.16	11.00	11.00	4.97

GHQ statistics: Recall, Communication, Social support, Sleep (12 month survivors).

			WITUPIOI			101GHQ6M	-		TTGHQ12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
		23.11	22.00	13.10	19.89	16.00	14.45	25.78	22.00	16.45
ume on icu vague recall	recali	22.32	22.00	10.96	20.77	18.00	14.77	18.41	13.00	12.50
	scall	26.17	21.00	21.40	24.67	20.50	18.57	26.17	23.00	18.66
patient ability to poor		20.08	19.00	11.43	19.76	15.00	14.47	21.16	17.00	15.37
		29.50	26.00	14.76	24.17	19.00	16.18	22.08	21.00	13.51
tod	lives with friend/partner/next of kin	24.93	22.00	14.11	20.67	16.00	14.32	20.41	15.00	14.16
following lives alo discharge nearby	lives alone next of kin nearby	18.25	15.00	10.12	23.50	20.50	19.51	23.88	20.50	18.08
lives ald support	lives alone no social support	18.50	18.50	6.36	19.00	19.00	2.83	26.00	26.00	8.49
ability to sleep good		49.00	49.00	•	14.00	14.00	•	18.00	18.00	
on ward	lable	24.16	22.00	14.38	20.84	21.00	13.30	21.26	13.00	15.46
poor		20.47	19.00	10.37	22.00	15.00	17.35	21.88	19.00	14.51

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SES statistics: Recall, Communication, Social support, Sleep (12 month survivors).

			SES1M			SES6M			SES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
patient recall of	no recall	17.89	20.00	8.34	16.89	18.00	8.64	18.56	22.00	8.76
time on Icu	vague recali	15.73	16.00	8.36	14.50	14.50	7.38	15.77	15.00	7.57
	high recall	17.00	19.00	9.44	15.83	17.00	9.62	16.83	16.50	11.21
patient ability to	poor	15.68	15.00	8.53	14.24	13.00	8.00	15.68	15.00	8.31
communicate on	Bood	18.08	18.50	8.03	17.50	17.50	7.50	18.58	16.00	8.37
social support anticipated	lives with friend/partner/next of kin	16.15	16.00	8.92	14.89	14.00	8.17	16.04	15.00	9.18
following discharge	lives alone next of kin nearby	18.75	21.00	6.52	16.88	18.00	8.06	18.75	16.50	6.04
	lives alone no social support	11.50	11.50	6.36	14.50	14.50	4.95	16.00	16.00	1.41
ability to sleep	boog	32.00	32.00	•	13.00	13.00	-	15.00	15.00	•
on ward	reasonable	15.47	15.00	9.18	14.84	17.00	9.42	16.32	15.00	9.40
	poor	16.65	18.00	6.73	15.94	17.00	6.26	17.06	16.00	7.48

IOES statistics: Recall, Communication, Social support, Sleep (12 month survivors).

			IOES1M			IOES6M			IOES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
patient recall of no recal	call	16.56	14.00	12.24	14.33	12.00	13.20	14.33	9.00	14.35
time on icu vague	vague recall	12.95	11.50	8.97	12.05	10.00	9.60	10.23	3.50	12.44
high	high recall	12.17	13.50	9.79	10.67	10.50	9.67	12.17	13.50	8.84
		13.76	14.00	9.87	12.28	9.00	10.61	9.92	3.00	12.08
5		13.58	11.50	10.14	12.58	13.00	10.22	14.92	16.00	12.41
social support lives with anticipated friend/pai	ives with riend/partner/next of kin	13.41	12.00	9.99	11.70	12.00	10.45	10.74	8.00	11.65
	lives alone next of kin nearby	14.00	14.00	10.49	14.38	11.50	11.38	12.88	7.00	14.08
lives ald support	lives alone no social support	16.50	16.50	9.19	13.50	13.50	7.78	17.00	17.00	19.80
sleep		26.00	26.00	•	7.00	7.00	•	3.00	3.00	•
on ward reaso	reasonable	11.74	11.00	10.44	10.47	7.00	10.70	8.53	4.00	11.23
poor		15.18	14.00	8.82	14.82	14.00	9.97	15.41	15.00	12.81

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GHQ statistics: Occupational class, Mode of admission (12 month survivors)

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			TOTGHQ1M			TOTGHQ6M			TTGHQ12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
class by	Professional	22.00	24.00	4.85	25.80	19.00	22.86	26.80	22.00	19.97
occupation	Managerial/technical	20.38	17.00	7.74	17.00	16.00	8.09	18.38	17.00	6.32
	Clerical /minor supervisory	17.11	22.00	7.94	15.67	13.00	7.87	17.67	11.00	12.67
	Semi-skilled manual	29.46	25.00	18.97	24.85	16.00	18.49	24.46	20.00	18.19
	Student	23.00	23.00	1.41	27.50	27.50	12.02	18.00	18.00	8.49
Mode of	Elective	21.10	22.00	9.74	18.05	15.50	12.98	21.75	19.50	13.01
admission	Ward conscious	65.00	65.00	•	58.00	58.00	•	58.00	58.00	•
	Ward unconscious	14.00	14.00	1.41	16.00	16.00	1.41	14.00	14.00	1.41
	A/E conscious	28.00	28.00	4.24	21.00	21.00	14.14	30.00	30.00	26.87
	A/E unconscious	26.13	22.00	16.41	24.25	24.00	15.00	19.88	19.00	15.25
	OT unplanned	19.00	20.50	10.92	24.25	18.00	21.36	13.50	10.00	9.26

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SES statistics: Occupational class, Mode of admission (12 month survivors).

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×				SES1M			SES6M			SES12M	
Network         Mean         Median         Deviation         Median         Deviation         Me           Professional         15.00         16.00         9.00         14.00         17.00         7.42         Minot           Managerial/technical         13.50         16.50         7.23         12.75         15.50         7.42           Clerical /minor         13.50         16.50         7.23         12.75         15.50         6.18           Semi-akilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Student         18.50         18.50         7.11         22.00         22.00         1.41           Ward conscious         4.50         4.50         7.82         15.45         17.00         7.21           Ward conscious         4.50         4.50         7.82         15.45         17.00         7.21           Ward conscious         4.50         4.50         4.55         4.50         4.95         7.78           Ward unconscious         19.00         17.00         7.31         19.50         7.78         17.00         7.71           Of unplanned         13.25         15.50         8.49         19.55					Std			Std			Std
Professional         15.00         16.00         9.00         14.00         17.00         7.42           Managerial/ fechnical         13.50         16.50         7.23         12.75         15.50         6.18           Clerical / minor         12.44         13.00         6.67         11.22         11.00         7.03           Semi-skilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Semi-skilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Semi-skilled manual         21.31         25.00         8.73         19.15         23.00         7.21           Student         18.50         18.50         7.82         15.45         17.00         7.21           Ward unconscious         4.50         4.50         28.00         7.82         4.50         4.50         4.95           Ward unconscious         4.50         4.50         4.95         4.50         4.95         7.21           Ward unconscious         19.00         17.00         7.35         15.50         8.03         7.78           OT unplanned         13.25         15.50         9.57         12.00         <			Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
Managerial/ technical         13.50         16.50         7.23         12.75         15.50         6.18           Clerical /minor         12.44         13.00         6.67         11.22         11.00         7.03           Supervisory         21.31         25.00         8.73         19.15         23.00         8.48           Semi-ekilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Semi-ekilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Student         18.50         7.1         22.00         28.00         7.03         7.21           Ward conscious         16.45         18.00         7.82         15.45         17.00         7.21           Ward unconscious         28.00         28.00         28.00         28.00         7.21         7.21           Ward unconscious         4.50         4.50         4.56         4.50         4.95         4.95           AF unconscious         19.00         17.00         7.95         16.38         15.50         8.03           OT unplanned         13.25         15.50         9.57         12.50         9.04         9.04	class by	Professional	15.00	16.00	9.00	14.00	17.00	7.42	14.80	16.00	11.43
Clerical /minor12.4413.006.6711.2211.007.03supervisory supervisory21.3125.008.7319.1523.008.48Semi-ekiled manual21.3125.008.7319.1523.008.48Student student18.507122.0023.008.48Student tective16.4518.007.122.007.21Ward conscious16.4518.007.8215.4517.007.21Ward unconscious4.504.954.954.504.954.95AF conscious19.0017.007.9516.3815.508.03OT unplanned13.2515.509.5712.5013.009.04	occupation	Managerial/ technical	13.50	16.50	7.23	12.75	15,50	6.18	14.13	14.00	7.41
Semi-ekilled manual         21.31         25.00         8.73         19.15         23.00         8.48           Student         18.50         18.50         71         22.00         22.00         1.41           Student         18.50         71         22.00         22.00         7.21           Student         16.45         18.00         7.1         22.00         7.21           Ward conscious         16.45         18.00         7.82         15.45         17.00         7.21           Ward unconscious         28.00         28.00         28.00         7.82         15.45         17.00         7.21           Ward unconscious         4.50         4.50         4.50         28.00         7.21           Ward unconscious         19.00         19.00         8.49         19.50         7.36         4.95           AF unconscious         19.00         17.00         7.95         16.38         15.50         8.03           OT unplanned         13.25         15.50         9.57         12.50         9.04		Clerical /minor supervisory	12.44	13.00	6.67	11.22	11.00	7.03	13.67	13.00	9.19
Student         18.50         18.50         18.50         71         22.00         22.00         7.41           Elective         16.45         18.00         7.82         15.45         17.00         7.21           Ward conscious         28.00         28.00         7.82         15.45         17.00         7.21           Ward unconscious         4.50         4.50         4.95         4.50         4.95         4.95           AF conscious         19.00         19.00         8.49         19.50         19.50         7.78           AF unconscious         19.00         17.00         7.95         16.38         15.50         8.03           OT unplanned         13.25         15.50         9.57         12.50         13.00         9.04		Semi-ekilled manual	21.31	25.00	8.73	19.15	23.00	8.48	21.08	22.00	6.46
Elective         16.45         18.00         7.82         15.45         17.00         7.21           Ward conscious         28.00         28.00         28.00         28.00         28.00         7.21           Ward unconscious         4.50         4.50         4.50         4.50         4.50         4.95           Ward unconscious         19.00         19.00         8.49         19.50         19.50         7.78           AF conscious         19.00         17.00         7.95         16.38         15.50         8.03           OT unplanned         13.25         15.50         9.57         12.50         13.00         9.04		Student	18.50	18.50	.71	22.00	22.00	1.41	15.50	15.50	2.12
Ward conscious         28.00         28.00         28.00         28.00         28.00         28.00         28.00         28.00         3.00         3.00         3.00         3.00         3.00         3.00         3.00         3.00         4.95         4.95         4.50         4.95         7.78         778	Mode of	Elective	16.45	18.00	7.82	15.45	17.00	7.21	18.15	16.00	8.09
ous         4.50         4.50         4.95         4.50         4.50         4.95           19.00         19.00         19.00         8.49         19.50         19.50         7.78           13.25         15.50         9.57         12.50         13.00         9.04	admission	Ward conscious	28.00	28.00		28.00	28.00	-	28.00	28.00	•
19.00         19.00         8.49         19.50         19.50         7.78           19.00         17.00         7.95         16.38         15.50         8.03           13.25         15.50         9.57         12.50         9.04		Ward unconscious	4.50	4.50	4.95	4.50	4.50	4.95	7.50	7.50	12.
US         19.00         17.00         7.95         16.38         15.50         8.03           13.25         15.50         9.57         12.50         13.00         9.04		A/E conscious	19.00	19.00	8.49	19.50	19.50	7.78	19.00	19.00	8.49
13.25 15.50 9.57 12.50 13.00 9.04		A/E unconscious	19.00	17.00	7.95	16.38	15.50	8.03	15.88	16.00	7.18
		OT unplanned	13.25	15.50	9.57	12.50	13.00	9.04	11.00	9.50	10.55

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IOES statistics: Occupational class, Mode of admission (12 month survivors).

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			IOES1M			IOES6M			IOES12M	
				Std			Std ·			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
class by	Professional	12.00	14.00	6.96	9.20	3.00	11.08	8.60	2.00	14.31
occupation	Managerial/technical	8.38	9.50	6.91	8.00	6.50	8.02	8.50	8.00	5.88
-	Clerical /minor supervisory	11.44	14.00	7.68	10.78	9.00	8.20	8.56	2.00	11.53
	Semi-skilled manual	18.23	24.00	11.81	17.08	20.00	10.92	17.00	17.00	14.47
	Student	20.00	20.00	12.73	14.50	14.50	20.51	9.00	<b>0</b> .00	12.73
Mode of	Elective	10.65	8.50	9.34	11.20	10.00	9.41	10.70	6.50	11.40
admission	Ward conscious	25.00	25.00	•	17.00	17.00	•	17.00	17.00	•
	Ward unconscious	7.00	7.00	7.07	6.00	6.00	8.49	6.00	6.00	8.49
	A/E conscious	20.00	20.00	11.31	16.00	16.00	16.97	19.00	19.00	21.21
	A/E unconscious	20.00	21.00	9.24	15.38	15.50	13.09	10.13	3.00	12.83
	OT unplanned	13.75	11.50	8.81	12.50	11.50	11.27	16.25	12.00	17.61

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GHQ statistics: Indication for admission, Sex (12 month survivors).

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			TOTGHQ1M			TOTGHQ6M			TTGHQ12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
Indication for	Respiratory	19.00	16.00	8.89	23.14	17.00	15.54	20.71	15.00	14.08
admission	Trauma	41.00	52.00	31.00	38.33	51.00	28.22	38.00	53.00	30.41
	Metab/endoo	18.00	18.00	5.66	15.00	15.00	8.49	14.00	14.00	8.49
	Transplant	19.38	22.00	7.15	20.46	17.00	15.07	21.77	17.00	15.13
	Plan.surgery	24.88	22.50	12.53	15.38	13.00	7.95	20.50	19.50	8.86
	Unplan.surgery	28.25	25.00	14.97	22.00	22.00	13.17	15.00	14.50	7.53
Sex	Male	22.48	22.00	13.12	21.36	17.00	14.84	22.92	20.00	15.05
	Female	24.50	23.00	13.78	20.83	17.00	15.89	18.42	12.50	13.77

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SES statistics: Indication for admission, Sex (12 month survivors).

			SES1M			SES6M			SES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
Indication for	Respiratory	15.29	13.00	9.14	15.43	14.00	9.29	16.29	13.00	8.12
admission	Trauma	21.33	26.00	9.87	22.00	26.00	8.72	22.33	27.00	8.96
	Metab/endoc	13.00	13.00	4.24	10.50	10.50	10.61	11.00	11.00	8.49
	Transplant	15.00	16.00	7.87	13.31	14.00	7.18	16.38	15.00	7.59
	Plan.surgery	19.00	19.50	6.99	18.75	17.50	5.68	19.63	16.50	9.40
	Unplan.surgery	16.25	16.50	13.12	12.00	12.00	9.02	10.50	12.50	7.59
Sex	Male	15.52	17.00	8.53	15.36	17.00	8.32	16.40	16.00	8.76
	Female	18.42	17.00	7.89	15.17	15.00	7.26	17.08	14.50	7.68

IOES statistics: Indication for admission, Sex (12 month survivors).

			IOES1M			IOES6M			IOES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
Indication for	Respiratory	17.57	14.00	10.23	15.43	12.00	12.05	14.43	9.00	16.44
admission	Trauma	27.00	25.00	5.29	24.33	23.00	8.08	22.33	17.00	9.24
	Metab/endoc	9.50	9.50	К.	4.00	4.00	5.66	1.50	1.50	2.12
	Transplant	10.38	00.6	8.71	10.85	12.00	8.16	9.62	2.00	12.26
	Plan.surgery	10.88	7.50	10.34	12.13	10.50	11.23	13.00	9.00	9.47
	Unplan.surgery	15.50	15.00	8.81	7.75	3.50	11.32	6.75	1.50	11.59
Sex	Male	14.04	12.00	9.90	11.56	12.00	10.87	11.16	8.00	12.28
	Female	13.00	14.00	9.90	14.08	11.50	9.37	12.33	7.00	12.67

GHQ statistics: Relatives, Muscle relaxants, Cancer, Life events (12 month survivors)

			TOTGHQ1M			TOTGHQ6M			TTGHQ12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
relative resident while	relatives resident	19.67	19.00	7.15	17.50	16.00	7.87	15.17	10.50	13.79
patient on icu	relatives not resident	23.81	22.00	14.04	21.90	17.00	15.98	22.68	20.00	14.67
paralysing agent	no paralysing agents	23.47	22.50	13.67	21.12	16.50	15.27	21.82	17.50	15.07
administered?	paralysing agents administered	19.33	22.00	4.62	22.00	21.00	13.53	17.33	20.00	8.33
cancer part of original	Patient has cancer	24.60	23.00	11.23	18.10	16.50	8.46	20.10	18.00	10.17
propert	Patient does not have cancer	22.59	22.00	13.99	22.33	17.00	16.74	21.96	18.00	16.09
life events in follow up	significant life events occurred	22.75	22.00	11.21	19.65	16.50	13.70	22.05	19.50	12.73
	no significant life events occurred	23.59	22.00	15.54	23.00	17.00	16.57	20.76	13.00	16.94

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SES statistics: Relatives, Muscle relaxants, Cancer, Life events (12 month survivors)

			SES1M			SES6M			SES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
relative resident while	relatives resident	15.00	18.50	8.49	14.33	16.00	7.39	12.00	13.50	7.80
battent on Icu	relatives not resident	16.74	16.00	8.42	15.48	17.00	8.09	17.52	16.00	8.24
paralysing agent	no paralysing agents	16.62	17.50	8.63	15.35	16.00	7.83	16.94	15.00	8.45
	paralysing agents administered	14.67	16.00	4.16	14.67	18.00	10.41	13.00	17.00	6.93
cancer part of original	Patient has cancer	17.70	18.50	9.03	16.10	17.00	7.77	17.50	16.50	8.83
	Patient does not have cancer	16.00	16.00	8.19	15.00	14.00	8.06	16.30	15.00	8.28
life events in follow up	significant life events occurred	18.40	19.50	7.66	16.60	17.50	6.72	18.90	17.00	7.48
	no significant life events occurred	14.18	15.00	8.74	13.76	14.00	9.05	13.94	13.00	8.68

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IOES statistics: Relatives, Muscle relaxants, Cancer, Life events (12 month survivors).

			IOES1M			IOES6M			IOES12M	
				Std			Std			Std
		Mean	Median	Deviation	Mean	Median	Deviation	Mean	Median	Deviation
relative resident while	relatives resident	14.17	11.50	9.24	14.00	14.00	9.23	9.17	8.50	8.68
patient on Icu	relatives not resident	13.61	12.00	10.07	12.06	8.00	10.66	12.00	8.00	12.88
paralysing agent	no paralysing agents	14.03	14.00	10.18	13.24	13.00	10.30	12.47	8.50	12.34
	paralysing agents administered	10.00	10.00	1.00	2.67	<u>8</u>	4.62	1.00	8.	1.73
cancer part of original	Patient has cancer	8.50	4.00	8.71	9.10	3.50	10.19	10.30	6.50	10.93
	Patient does not have cancer	15.63	14.00	9.64	13.59	12.00	10.32	12.00	9.00	12.86
life events in follow up	significant life events occurred	13.25	12.50	10.48	13.10	14.50	10.11	11.15	8.00	11.33
	no significant life events occurred	14.24	12.00	9.26	11.53	9.00	10.86	12.00	5.00	13.58

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### APPENDIX XIII:

### TEST STATISTICS AND SIGNIFICANCE LEVELS: SUBGROUP ANALYSIS

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Ag	e grou	p	Stay hospi	ital group	Admission sev	erity
Chi	squar	e p<	Chi square	p<	Chi square	p<
GHQ	2.59	0.5	1.38	0.7	3.09	0.4 .
6wks						
GHQ	2.21	0.5	0.67	0.9	4.01	0.3
6mo <b>s</b>						
GHQ	3.27	0.4	2.07	0.6	7.98	0.05
12mos						
SES	2.88	0.4	2.18	0.5	10.32	0.008
6wks						
SES	4.33	0.2	4.90	0.2	13.79	0.005
6mos						
SES	1.63	0.7	1.27	0.7	9.34	0.03
12mos						
IOES	7.45	0.06	1.90	0.6	3.17	0.4
6wks						
IOES	5.69	0.1	1.01	0.8	6.85	0.08
6mos						
IOES	4.41	0.2	1.41	0.7	0.68	0.9
12mos						

### Kruskal Wallis one way ANOVA: Values of chi square and significance levels.

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	<u>Recal</u>		Social sup	port	<u>Occupational</u>	<u>l class</u>	
C	Chi square	p<	Chi square	p<	Chi square	; p<	
GHQ	0.09	0.9	1.13	0.6	3.60	0.5	
6wks	1						
GHQ	0.22	0.9	0.22	0.9	2.56	0.6	
6mos	5						
GHQ	1.83	0.4	0.88	0.6	1.12	0.9	<u> </u>
12mc	)5						
SES	0.56	0.8	1.76	0.4 ·	7.98	0.1	
6wks	3	_					
SES	0.52	0.8	0.69	0.7	9.09	0.06	
6mos	;						
SES	0.66	0.7	0.83	0.7	5.37	0.3	
12mc	)S						
IOES	0.71	0.7	0.18	0.9	6.04	0.2	
6wks							
IOES	0.21	0.9	0.74	0.7	4.54	0.3	
6mos							
IOES	0.66	0.7	0.62	0.7	3.88	0.4	
12mc	S						

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### Kruskal Wallis one way ANOVA: Values of chi square and significance levels.

### Kruskal Wallis one way ANOVA: Values of chi square and significance levels.

### Indication for admission

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	Chi square	p<
GHQ	2.67	0.8
6wks		
GHQ	2.23	0.8
6mo <b>s</b>		
GHQ	2.17	0.8
12mos		
SES	2.50	0.8
6wk <b>s</b>		
SES	4.94	0.4
6mos		•
SES	4.10	0.5
12mos		
IOES	8.45	0.1
6wks		
IOES	6.61	0.3
6mos		
IOES	7.09	0.2
12mos		

### Mann Whitney U test: Values of U and significance levels.

	<u>St</u>	ayICU	Sleep		
	U	p<	U	p<	
GHQ	184.5	0.6	207.5	0.4	
6wks					
GHQ	150.0	0.5	208.5	0.9	
бтоя					
GHQ	60.5	0.01	158.5	0.7	
12mos			· · · · · · · · · · · · · · · · · · ·	·····	
SES	186.0	0.7	220.5	0.6	
6wks					
SES	103.0	0.04	203.0	0.9	
бтоѕ					
SES	70.5	0.03	161.0	0.8	
12mos	· · · · · · · · · · · · · · · · · · ·		· · · · · · · · · · · · · · · · · · ·		
IOES	147.5	0.2	204.0	0.4	
6wks					
IOES	171.5	0.9	175.5	0.4	
6mos					
IOES	128.5	0.8	106.0	0.05	
12mos					

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	<u>Comm</u>	unication	Se	x	Relatives'	presence	
	U	p<	U	p<	U	p<	
GHQ	76.5	0.02	140.5	0.8	82.5	0.7	
6wks							
GHQ	119.5	0.3	148.5	0.9	86.0	0.8	
6mos							
GHQ	129.5	0.5	119.5	0.3	54.5	0.1	
12mos							
SES	125	0.4	132.0	0.6	87.0	0.8	
6wks							
SES	113	0.2	143.0	0.8	83.5	0.9	
бтоз							
SES	121	0.4	146.5	0.9	58.0	0.1	
12mos		-					
IOES	150	1	144.0	0.8	87.5	0.8	-
6wks							
IOES	144.5	0.9	120.0	0.3	81.5	0.6	
6mos							
IOES	102	0.2	134.5	0.6	88.5	0.9	
12mos							

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### Mann Whitney U test: Values of U and significance levels.

	Mus	<u>cle relaxa</u>	ints		Cancer	Li	fe events	
		U	<b>p</b> <		U	p<	U	p<
GHQ	41.0	0.6		111.5	0.4	168.0	0.9	
<b>6wks</b>								
GHQ	44.0	0.7		130.5	0.9	159.0	0.7	
6mo <b>s</b>								
GHQ	46.5	0.8		127.0	0.8	139.0	0.3	
12mos								
SES	41.5	0.6		119.5	0.6	127.0	0.2	
6wks								
SES	49.0	0.9		128.5	0.8	140.0	0.4	
6mos								
SES	43.0	0.7		128.5	0.8	116.0	0.1	
12mos								
IOES	39.0	0.5		73.5	0.04	156.0	0.7	
6wks								
IOES	18.5	0.07		98.0	0.2	154.0	0.6	
6mos								
IOES	15.5	0.05		133.5	0.9	109.0	0.9	
12mos								

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### Mann Whitney U test: Values of U and significance levels.

### APPENDIX XIV

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SPEARMAN CORRELATION COEFFICIENTS AMONG TOTAL SCORES: GENERAL HEALTH QUESTIONNAIRE, SELF ESTEEM SCALE, IMPACT OF EVENT SCALE. Spearman correlation coefficients for mean GHQ, SES and IOES scores at all follow-up points.

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Correlations

		101GHQ1	TOTGHQ6	TIGHO12						
		₹	₹	₹	SES1M	SES6M	SES12M	IOES1M	IOES6M	IOES12M
ICIGH01M	Pearson Correlation	1.000		.598**	.587**	.498**	.472**	.377*	.184	.410
	Sig. (2-tailed)	•	000	000	000	.001	.003	.012	.250	.012
	z	44	41	37	44	4	. 37	44	41	37
TOTGHQ6M	Pearson Correlation		1.000	.726**	.520**	.531**	.515**	.384*	.347*	<b>*</b> 695.
	Sig. (2-tailed)	<u>80</u> .	•	000	000.	000	.00	.013	.026	000
	z	41	41	37	41	41	37	41	41	37
TTGHQ12M	Pearson Correlation	.598**	.726**	1.000	.527**	.583**	.684**	.442**	.429**	-451-
	Sig. (2-tailed)	800. 000:	000	•	.001	000	000	900.	800.	.005
	z	37	37	37	37	37	37	. 37	37	37
SES1M	Pearson Correlation	.587**	.520**	.527**	1.000	.820**	.758**	.477.	.342*	.360
	Sig. (2-tailed)	000.	000	.001	•	000.	000.	.001	.029	.029
	z	44	41	37	4	4	37	44	41	37
SES6M	Pearson Correlation	.498**	.531**	.583**	.820**	1.000	.789	.387*	.436**	.446
	Sig. (2-tailed)	.001	000.	000	000	•	000	.012	.004	900.
	z	41	41	37	41	41	37	41	41	37
SES12M	Pearson Correlation	.472**	.515**	.684**	.758**	.789**	1.000	.299	.437**	.447*
	Sig. (2-tailed)	£00 <sup>.</sup>	.00 <sup>.</sup>	000	000.	000	•	.072	.007	900.
	z	37	37	37	37	37	37	37	37	37
IOES1M	Pearson Correlation	.377*	.384*	.442**	**774.	.387*	.299	1.000	.781	.472
	Sig. (2-tailed)	.012	.013	900.	.001	.012	072	٠	000.	E00 <sup>.</sup>
	z	44	41	37	44	41	37	44	41	37
IOES6M	Pearson Correlation	.184	.347*	.429**	.342*	.436**	437-	.781**	1.000	.737*
	Sig. (2-tailed)	.250	.026	.008	.029	<b>6</b> 00.	.007	000.		<b>00</b> .
	z	41	41	37	41	41	37	41	41	37
IOES12M	Pearson Correlation	.410*		.451**	.360*	.446	447	.472	.737**	1.000
	Sig. (2-tailed)	.012	000	.005	.029	.006		.003	000	•
	z	37	37	37	37	37	37	37	37	37

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\* Correlation is significant at the 0.05 level (2-tailed).