

THE UNIVERSITY OF HULL

**The Role of Family Factors in Patients' And Relatives' Psychological
Adjustment To Intensive Care: A Comparison With An Elective
Cardiac Surgery Group.**

being a Dissertation submitted in partial fulfilment of the requirements
for the Degree of Doctor of Clinical Psychology

In the University of Hull

By

Ellen Young B.Sc. (Hons)

July 2002

CONTENTS

	PAGE(S)
ACKNOWLEDGEMENTS	1
ABSTRACT	2
INTRODUCTION	3-51
Overview Of Introduction	3
i) – Psychological problems in ITU	4-17
ii) – ‘Individual Health Psychology’ - Models and research	18-44
iii) – Family Health Psychology Model	45-46
iv) – Research Model	47-48
Research Questions	49-51
METHOD	52-83
Design	52-56
Setting Characteristics	57-61
Participants	62
Recruitment	63-65
Measures	66-77
Procedure	78-81
Analysis	82-83

CONTENTS CONTINUED....

	PAGE(S)
RESULTS	84-118
Outline of results	84
Participant demographics	84-92
Statistical Analysis	93
Group Differences	94-98
Open Question analysis	99-101
Relationships between variables	102-105
Post-Hoc analysis	106-111
Testing the Research Model	112-116
Specific ITU related Question	117-118
DISCUSSION	119-140
Interpretation of findings	119-129
Clinical Implications of the Research	130-132
Methodological Considerations	133-136
Research Implications	137-139
Conclusion	140
REFERENCES	141-159
APPENDICES:	
APPENDIX 1: Patient Information Sheet – ITU Group	
– Ward Recruitment.	

CONTENTS CONTINUED....

APPENDIX 2: Relative Information Sheet – ITU Group

- Ward recruitment

APPENDIX 3: Consent Forms A & B

APPENDIX 4: Contact Information Sheet

APPENDIX 5: Patient Information Sheet – ITU Group

- Postal recruitment

APPENDIX 6: Relative Information Sheet – ITU Group

- Postal Recruitment

APPENDIX 7: Patient Information Sheet – Elective Cardiac

Surgery Group

APPENDIX 8: Relative Information Sheet – Elective Cardiac

Surgery Group

APPENDIX 9: Registrar Generals Standard Occupational

Classification (SOC-2000).

APPENDIX 10: Hospital Anxiety and Depression Scale

(HADS)

APPENDIX 11: Family Assessment Device (FAD)

APPENDIX 12: Severity of Illness Continuum

APPENDIX 13: Research Timeline

APPENDIX 14: Ethical Approval

LIST OF FIGURES AND TABLES

Figures:

Figure 1: The Biopsychosocial Model (p.19)

Figure 2: Crisis Theory (p.20)

Figure 3: Research Model (p.48)

Figure 4: Summary of Design (p.56)

Figure 5: Carter and McGoldrick's Six Stages of The Family Life Cycle (p.68)

Figure 6: The Relationship between Family Functioning Difference Scores and Anxiety – ITU Relatives (p.108)

Figure 7: The Relationship between Family Functioning Difference Score and Depression – ITU Relatives (p. 109)

Figure 8: Revised Research Model (p.113)

Tables:

Table 1: The Number of Accepted Referrals per Admitting Speciality for 2001. (p.58)

Table 2: Descriptive Data for Gender And Age in the ITU and Elective Cardiac Sugery Group. (p.85)

Table 3: Breakdown of Socio-Economic Classes Within the ITU and Elective Cardiac Surgery Groups. (p.86)

Table 4: Frequency of Family Life-Cycle Stage for ITU and Elective Cardiac Surgery Groups. (p.87)

Table 5: Presenting Ilneeses of the ITU Group. (p.88)

Table 6: Frequency of Surgery Type for Elective Cardiac Surgery Group.(p.89)

Table 7: Descriptive Data for Illness Variables of ITU and Elective Cardiac Surgery Patients. (p.90)

Table 8: Prevalence Rates of Anxiety and Depression for Patients and Relatives (HADS>10) In the ITU and Elective Cardiac Surgery Group. (p.91)

Table 9: T-test analysis of Difference between Patients and Relatives in the ITU Group. (p.92)

Table 10: Independent Samples T-test results for differences between ITU and Elective Cardiac Surgery patients on the Measures of Psychological Adjustment. (p.95)

Table 11: Independent Samples T-test Results for Differences Between ITU and Elective Cardiac Surgery Relatives on the Measures of Psychological Adjustment. (p.96)

Table 12: Independent Sample T-test Results Examining the Difference between ITU and Elective Cardiac Surgery Patients on Perceived Family Functioning. (p.98)

Table 13: Main Themes Produced from Thematic Analysis. (p.100)

Table 14: Partial Correlation Coefficients for the ITU Group. (p.103)

Table 15: Partial Correlation Coefficients for the Elective Cardiac Surgery Group.(p.105)

Table 16: Paired Samples T-test Analysis of the Difference between Patients' and Relatives' Perceptions of Family Functioning within the ITU and elective cardiac surgery groups. (p.107)

Table 17: Stepwise Multiple Linear Regression Findings Using Relatives Anxiety as the Dependent Variable. (p.115)

Table 18: Stepwise Linear Regression Findings Using Relatives Depression as the Dependent Variable. (p.115)

Table 19: Stepwise Multiple Linear Regression Findings using Relatives Perceptions of Family Functioning as the Dependent Variable. (p.116)

Table 20: Paired Samples T-test Analysis between Patients and Relatives Perceptions of Illness Severity while in ITU. (p.117)

ACKNOWLEDGEMENTS

I would like to thank my academic supervisors, Mike Wang and Lesley Glover.

Thanks to Mike for all the support, encouragement and advice during the early stages of the research. Special thanks go to Lesley Glover for her patience, unwavering support and valued advice during writing up.

Many thanks to Rachel Waddington from the University of Hull for her statistical advice.

Thanks also go out to all those at Manchester Royal Infirmary, who helped with the research and welcomed me in to their teams. Janice, Sarah, Lucy and Jane from the ITU follow-up team were a huge support. Their enthusiasm and dedication to the research made data collection an enjoyable experience and without them the research would have not been possible. Many thanks also to Stuart Jones and the cardiac liaison team whose help with the recruitment and provision of rooms is greatly appreciated.

Also, many thanks go out to those patients and relatives who participated in the research. Thanks are not only for their participation but also for allowing me the opportunity to learn so much from their experiences.

Finally, a huge thank-you to my family for all their support. Particular thanks to James for patiently allowing our life to be put on hold.

ABSTRACT

Intensive Treatment Unit (ITU) patients and relatives have been shown to have high levels of psychological distress post-ITU discharge. However little of the research to date has attempted to establish if the psychological distress experienced is greater than other medical groups or to explore those factors which may predict psychological adjustment. This is despite claims in the literature that ITU patients are 'unique'. The present study attempted to address some of the literatures limitations. The 'uniqueness' of ITU patients was addressed by comparison with a matched elective cardiac surgery group. Family factors (family functioning and relatives' adjustment) and discrepancies in perceptions of illness severity were explored to see if they could account for the variance in patients' and relatives' adjustment.

Twenty ITU and fifteen elective cardiac surgery patients and their closest relatives participated in the research. The main findings revealed that ITU relatives perceived themselves to be significantly more depressed and perceived their family's functioning to be significantly more unhealthy than elective cardiac surgery relatives. ITU relatives were also significantly more anxious than ITU patients. No differences were found for patients between the groups. Family functioning and psychological adjustment were significantly correlated for relatives but not for patients. The following conclusions were drawn from the study; ITU relatives may be a 'unique' population, relatives require psychological support; and family functioning and psychological adjustment are significantly related for relatives but not patients. It may be that different models of adjustment are needed for patients and relatives. The findings are discussed in relation to clinical and research implications and methodological limitations.

OVERVIEW OF INTRODUCTION

The aim of the current project was to investigate the psychological adjustment of adult patients and relatives who have experienced an extended Intensive Treatment Unit (ITU) admission. The introduction has been divided into four main sections. These reflect the logical progression of the thesis from original research ideas to a consideration of relevant theory and empirical data which led to the formulation of the research model. In order to introduce the reader to the Intensive Care, Section I will begin with a brief literature review of the current research in to psychological problems in intensive care. A critique of this literature will follow from which several research questions will be proposed. This will then be followed with a discussion of the relevant models and literature which underlie the research questions. Section II will cover psychological models and research presented by the individual health psychology literature. Section III will discuss Rolland's Family system Illness Model put forward by the family health psychology literature. Section IV will end the introduction by presenting the research model for the current study. This model will incorporate the theory and research discussed throughout the introduction as well as considering the criticisms of previous research.

SECTION I

A BRIEF LITERATURE REVIEW OF PSYCHOLOGICAL ISSUES FOR THE ADULT INTENSIVE TREATMENT UNIT (ITU) PATIENT AND THEIR FAMILY

The ITU literature examining psychological issues can be divided into five main areas:

- **Psychological problems while the patient is in intensive care - The ITU syndrome.**
- **Patients' experiences and memories of being critically ill.**
- **Interventions aimed at ameliorating aversive experiences of ITU**
- **Long term psychological effects of critical illness for the patient.**
- **The impact of intensive care for the patients' relatives/family.**

Given that the present research is concerned with psychological adjustment during the 'recovery period', the first two sections will be described very briefly. Literature and research focusing on the longer term effects of critical illness will be discussed in greater detail.

Psychological Problems While The Patient Is In Intensive Care - The ITU Syndrome

The majority of research examining psychological problems has focused on the description and controversy surrounding the 'ITU syndrome'. This is a delirium like presentation often noted in ITU patients. Patients present with symptoms of; disorientation, hallucinations, paranoia, restlessness and combativeness (Soar, 1999)

as well as agitation, delusions and irritability (Pressman, Meyer, Peterson, Greenspon & Figueroa, 1997). Development of the syndrome has been thought to be detrimental to the patients' physiological condition and to impede recovery (Nuttall, Kumar & Murray, 1998; Tess, 1991; Schwabb, 1994). It is somewhat of a controversial term with much debate surrounding its aetiology (McGuire, Basten, Ryan, & Gallagher, 2000; Sitzman, 1993; Fisher and Moxham, 1984; Briggs, 1991). Environmental factors such as noise (Hansell, 1984), sleep deprivation (Granberg et al., 1996), separation and isolation (Mackellaig, 1990), immobilisation (Granberg et al., 1996) and communication difficulties (Granberg et al., 1996) have been suggested as causes of the syndrome alongside physiological aetiologies (Gelling, 1999). Literature on the ITU syndrome is in the majority a mixture of discursive accounts of the syndrome with limited reference to psychological theory or the formulation and testing out of research questions.

Patients' Experiences And Memories Of Being Critically Ill

Interest in patients' experiences and recollections of their stay in intensive care is a more recent advance in the literature, and only a few studies exist which have examined this area. A predominant finding of these studies is that patients have no memories or fragmentary memories for factual events during their stay in ITU (Jones, Hoggart, Withey, Donaghue & Ellis, 1979; Turner, Briggs, Sprighorn, Potgeiter, 1990; Jones, Griffiths & Humphris, 1999a; Compton, 1991; Jones, Griffiths & Humphris, 2000). Interestingly however, patients often recall periods of confusion involving vivid memories of nightmares and hallucinations (Jones et al, 1979; Laitenen, 1996; Jones et al., 1999a; Jones et al., 2000; Jones, Humphris & Griffiths, 1998). The lack of factual memories of ITU is believed to contribute to the reality

with which patients experience these nightmares and hallucinations, and the difficulty they experience in trying to distinguish them from reality (Jones et al, 1998).

Compten (1991) interviewed patients after they were discharged home and reported that patients tended to underestimate the severity of their illness. Patients felt that it was not until they entered the recovery phase that they realised how ill they had been.

Comptens' (1991) findings suggested that the recovery phase was a more stressful experience for patients, with reports of depression, anxiety and feelings of vulnerability.

Interventions Aimed at Ameliorating Aversive Experiences of ITU

Much discussion has occurred within the ITU literature as to nursing interventions which could take place to ameliorate the aversive experience which some patients have in ITU. Amongst this has been interventions aimed at preparing people for ITU prior to an admission. Pre-operative booklets and visits have been suggested (MacKellaig, 1990). However this is obviously only possible for those patients who are having a planned admission.

During the ITU stay articles have recommended interventions aimed at promoting sleep (Gelling, 1999), reducing noise levels (Kido, 1991), familiarising patients to their environment (Gelling, 1999) and facilitating communication (Gelling, 1999).

Post ITU interventions have been suggested which include the provision of post ITU information booklets (MacKellaig, 1990), return visits to ITU (Curtis, 1999) and

support groups for patients and relatives (Jones et al. 1998; Griffiths et al., 1996; Jones & O'Donnel, 1994).

ITU services have also begun providing patients with a follow up service after ITU discharge. The aim of this is to monitor psychological and physical recovery and normalise reactions such as amnesia and temporary cognitive deficits. Some ITU services have therefore changed practices and service provision to ameliorate some of these aversive effects of ITU.

Long Term Psychological Effects Of Critical Illness

To date the majority of the literature has focused on the immediate psychological problems experienced by ITU patients as they are in ITU. Consideration of the long term psychological effects of the ITU experience has begun to take place within the last decade (Griffiths, Jones and MacMillan, 1996; Skirrow, Jones, Griffiths & Kaney, 2001; Griffiths & Jones, 1999; Jones & O'Donnell, 1994; Jones, Griffiths, MacMillan & Palmer, 1994a; Eddleston, White & Guthrie, 2000; Jones et al., 1998). Indeed, research in this area has raised awareness of long term psychological problems such that a recent government paper 'Comprehensive Critical Care: Report of an Expert Group' (Department of Health, 2000) has reinforced that all British ITU's should provide patients with a follow up service after they have been discharged from ITU.

Due to the infancy of this area of research, the literature is still relatively small and is made up of mostly discussion articles, reviews and papers discussing the setting up and provision of follow-up clinics, support groups and provision of discharge booklets (Jones et al., 1998; Griffiths et al., 1996; Skirrow et al., 2001; Griffiths & Jones, 1999;

Jones & O'Donnell, 1994; Jones, Macmillan and Griffiths, 1994b; Jones et al., 1994a). The majority of research studies have focused on the identification and prevalence of psychological difficulties expressed after the patient has been discharged from ITU.

Common psychological problems which have been identified when following up patients are; recurrent nightmares, agoraphobia, panic, confusion, anger and conflict, fear of dying, depression, anxiety and guilt (Jones et al, 1998). Post-traumatic Stress Disorder (PTSD) is also believed to affect some patients (Jones et al., 2000) with prevalence rates of 27.5% (Schelling, Stoll, Meier, Haller, Briegel, Manert, Hummel, Lenhart, Heyduck, Polasek, Meier, Preuß, Bullinger, Schuffel & Peter, 1998) and 15% (Koshy, Wilkinson, Harmsworth, & Waldman 1997) being reported. This is believed to be related to the number of vivid memories of nightmares and persecutory hallucinations which patients recall (Schelling et al, 1998). Indeed it is PTSD, anxiety and depression which have been most frequently monitored and reported in the literature.

Jones et al. (1994a) completed a long term follow up study of 28 patients who had an ITU stay of greater than 4 days. Patients were followed up on discharge to the wards and at 2 and 6 months post-ITU discharge. Psychological adjustment was measured using the Profile of Mood States (POMS) questionnaire. At two months follow-up 43% of patients were experiencing anxiety and this rose to 55.5% at 6 months post-discharge. They showed that patients fell in to three categories in relation to how psychological problems were reported. These were;

1. Patients who exhibited immediate psychological distress which remained with them
2. Patients who experienced problems but were less affected with time
3. Those with a delayed onset of psychological distress, 6 months post discharge.

This study is the earliest in trying to establish a profile of psychological problems and prevalence rates. It does however suffer from a small sample size. Another potential problem with this study is the use of the POMS. Research which has followed this has tended to use different assessment tools, such as the Hospital Anxiety and Depression Scale (HADS). Comparisons of POMS detected anxiety and depression with HADS detected anxiety and depression may be limited.

Jones, Skirrow, Griffiths, Humphris, Dawson, Eddleston, Waldmann and Gager (2001b) carried out a large intervention study using 128 patients. This trial took place over three ITU's in Liverpool, Manchester and Reading. It utilised a randomised controlled trial to establish if the use of self-help rehabilitation manuals would alleviate patient distress and improve physical and psychological recovery. Prevalence rates for anxiety and depression taken at 6 months post-ITU discharge revealed that 33% of those patients who were allocated to the control group, and therefore received no intervention, had scores in the clinical range (>10) on the anxiety scale of the Hospital Anxiety and Depression Scale (HADS). Twelve per cent of control patients followed up at 6 months had scores in the clinical range (>10) of the depression scale of the HADS.

Eddleston et al. (2000) at Manchester Royal Infirmary (MRI) assessed 143 ITU patients at three months post ITU discharge. They utilised the HADS and found lower

adjustment rates of 11.9% for anxiety and 9.8% for depression. The cut-off for caseness used on the HADS is lower in this study (≥ 8). This is in comparison with the intervention study of Jones et al. (2001b) where the cut-off of >10 was used. This further extenuates the difference in psychological adjustment between these two research centres and yet also makes comparison of these two groups difficult.. The lower rates reported in the Eddleston et al. (2000) study are interesting as they raise questions about why discrepancies across units may exist. While these studies are attempting to establish the prevalence of ITU related psychological distress, it is important that the conclusions drawn from these studies should also consider the potential differences that may exist across units. Differences in ITU units and their sedation practices, layout, philosophies, follow up practices etc. will occur across the country. Some of these reasons and undoubtedly many more will contribute to the difference in prevalence rates.

It is evident from these prevalence rates that more data is required on psychological adjustment in ITU populations before we can fully understand the 'typical' psychological adjustment of the ITU patient. Future prevalence research should attempt to use a common cut-off score to aid with comparisons.

Another long term psychological problem which has been researched, concerns patients' amnesia for their time in ITU. Jones et al. (2000) argue that the amnesia experienced is likely to impact on the psychological health of patients after they have left ITU. The amnesia means that patients are unable to make sense of their experience, have little factual information to enable them to disregard hallucinations as unreal experiences (Jones, Griffiths, & Humphris, 2000), and are often left with

unrealistic expectations about their recovery (Jones et al., 1994a). The amnesia for this time is reported by patients as distressing (Griffiths et al., 1996).

There is a general feeling in this small body of literature that patients will be helped by learning about their experiences in the ITU, and thus filling in the “gaps” in their memory (Griffiths et al., 1996; Jones et al., 1994a; Jones et al., 1998; Jones et al., 2000). Jones et al. (1999a) conducted structured interviews with 17 ITU patients one week after ITU discharge. They found patients displayed either fragmentary memory of factual events or no memory of factual events. Anxiety was assessed using the HADS. They showed that those patients with factual memories of ITU displayed less anxiety post-ITU and argue that the acquisition of factual memories may help patients to reduce post-ITU psychological distress. This finding is supported by a further study in which Jones, Griffiths & Humphris (2001a) concluded that the memories of delusional experiences in ITU were related to the development of acute PTSD symptoms and that factual memories acted to protect against PTSD.

In light of these findings the above authors have attempted to provide patients with psychological interventions. These have been developed in the form of discharge booklets explaining potential problems and outlining realistic courses of recovery, as well as the formation of support groups for patients and relatives (Jones et al. 1998; Griffiths et al., 1996; Jones & O’Donnel, 1994).

Amongst this small body of research and literature are claims that the ITU population is a ‘unique’ sample of medical patients. Both Jones et al. (1998) and Skirrow et al. (2001) argue that the physical changes and amnesia for their time in ITU makes this

sample of patients 'almost unique' (Jones et al., 1998). They report that due to patients' amnesia they often underestimate how ill they have been and often have unrealistic expectations about their recovery (Griffiths et al., 1996). This is hypothesised to lead to tensions between patient and relatives when the patient returns home (Griffiths et al., 1996). This tension may contribute to psychological maladjustment. Such claims have however never been challenged or tested by comparison with another medical group who have experienced illness with threat to life, but without the experience of an extended ITU stay.

The Impact Of Intensive Care For The Patients Relatives/Family

Little research to date has focused on the effect of the ITU experience for the relatives and families of those in ITU. That which exists focuses on the needs and reactions of relatives during the intensive care stay (Foss and Tenholder, 1993; Kleiber, Halm, Titler, Montgomery, Johnson, Nicholson, Craft, Buckwalter & Megivern 1994; Kleeman, 1989; Johnson, Craft, Titler, & Halm, 1995; Breu and Dracup, 1978). The majority of research examining families functioning, coping and adjustment to critical illness/injury has been carried out in North America and examines effects on families whilst the patient is in the ITU (Leske and Jiricka, 1998; Twibell, 1998; Grossman, 1995; Kreamer, 1990; Reider, 1989).

The long term effects i.e. the consequences of critical illness on the family when the patient returns home, is a largely under researched area. British research has begun to document the prevalence of anxiety and depression in relatives both during the crisis time when patients are in ITU (Jones & Griffiths, 1995), at two weeks post-ITU discharge (Jones, Griffiths and Humphris, 1999b) and more recently (Jones, Skirrow,

Griffiths, Humphris, Dawson & Eddleston, 1999c) during follow up at 3, 6, and 12 months. Prevalence rates of anxiety (HADS >10) during the ITU stay have been recorded as 75% (Jones & Griffiths, 1995) in a sample of 16 patients. At two weeks post-ITU discharge prevalence rates for relatives have been calculated at 67% for anxiety and 37% for depression (Jones et al., 1999b). This study utilised the cut-off of >10 on the HADS and involved 30 relatives. Jones et al. (1999c) report 28% anxiety at 2 months and 32% at 6 months in a sample of 54 (at 2 months) and 38 (at 6 months) relatives.

These studies agree that a high proportion of relatives experience clinically significant levels of anxiety and depression. Only one of these studies (Jones et al., 1999c) however examines the longer term psychological impact of ITU for relatives and this study only measures relatives' anxiety.

A comparison of relatives' psychological distress with patients is possible by comparing the 6 month anxiety prevalence rates from the Jones et al.'s (1999c) study with the 6 month prevalence rates obtained from the intervention study carried out with patients (Jones et al., 2001b). The prevalence rates are 32% and 33% respectively. It is apparent then from this small body of data that patients and relatives suffer from similar levels of anxiety post-ITU.

The importance of studying relatives is apparent in that they are a population, who experience psychological distress and may be in need of support. Other reasons for studying this group are related to the effects of social support on patient recovery after illness (DiMatteo and Hays, 1981). Although this need is recognised by clinicians, the

majority of follow up groups currently running assess only the patient. Research into relatives' psychological adjustment and the interaction between patients' and relatives' adjustment is also under researched.

SUMMARY OF THE MAIN FINDINGS AND CLAIMS OF THE ITU

LITERATURE

The majority of literature addressing psychological problems of ITU patients has focused on the ITU syndrome, although this literature is not empirical. However recent trends in the literature have been to examine the long term effects of ITU for the patient and the relative. High anxiety and depression prevalence rates have been reported. However these prevalence rates are still limited in that there are only two studies for patients and one long term follow up for relatives. There are also problems in the patients' prevalence rates in that the two studies have utilised different cut-off scores. Differing rates of anxiety and depression across ITU units is also apparent, although this has not been addressed by the literature.

With the exception of Jones et al's (2000) study of the relationship of memory to psychological adjustment, there has been no attempt to use psychological models to help explain the variance in psychological adjustment of ITU patients or relatives. Given that physical health status has been found to be unrelated to psychological adjustment (Grossman, 1995; Arpin, Fitch, Browne and Corey, 1990) other factors in the social and psychological area should be investigated. The literature has also failed to look at the relationship between ITU patients' and relatives' psychological adjustment.

The recovery period has been highlighted by patients as the most stressful time (Laitenen, 1996). However very little is known about what happens during this time and how the environment into which they are discharged (the family home) influences psychological recovery. Tensions between relatives and patients have also been

discussed and it has been hypothesised that these are due to differing perceptions of severity of illness while the patient was in intensive care and memory difficulties.

However the literature has not attempted to test these hypotheses.

There have also been claims that ITU patients are a 'unique' sample. However there has been no attempt to ascertain if such claims are valid by comparison with another medical group with similar threat to life. There are some obvious gaps in this small body of literature. Three main research questions are therefore proposed from this literature review:

- 1. Are ITU patients and their relatives a 'unique' sample?**
- 2. What influence do family factors (family functioning and relatives' adjustment) have on psychological adjustment of patient and relative.**
- 3. Do patients and relatives differ in their recollections of ITU illness severity and does this difference impact on psychological adjustment?**

Research addressing these questions will ultimately provide clinicians with tools to help more effectively those patients who develop psychological problems. Ultimately, it will help in policy planning aimed at the prevention of ITU related psychological distress. Given that the 'recovery period' has been highlighted as the most stressful by patients and that patients are typically discharged into the family home, it seems highly relevant to explore how the family environment might influence psychological adjustment of both patient and relative.

Theoretical models of adjustment which consider both the patient and relative will be used as a guide to shape the research hypotheses. Specific attention will be paid to those theories which consider the role of family factors in adjustment.

Proposed models of adjustment and factors which contribute to adjustment will be discussed in the following chapters. Research which considers the role of the family in adjustment will also be discussed.

SECTION II

INDIVIDUAL HEALTH PSYCHOLOGY – MODELS AND LITERATURE RELATING TO THE INFLUENCE OF FAMILY ON HEALTH OUTCOMES

THEORIES AND MODELS OF ADJUSTMENT TO ILLNESS

Mainstream adult health psychology is a growing area of psychology which has enjoyed a wealth of literature and research. However, despite the recognition of peoples' social environment as an influence over illness the mention of relatives or family in health psychology texts and literature is scarce. Little examination of relatives' adjustment or the influence of family factors on patients' adjustment has occurred. This is in comparison to the wealth of literature on individual factors, such as coping and illness representations. As is evidenced from the models presented below, they are designed to explain illness or adjustment outcome in patients. Models examining relatives adjustment do not appear in health psychology literature. For this reason, mainstream adult health psychology will be referred to as 'individual health psychology' due to the focus on the individual (Akamatsu, Stephens, Hobfoll and Crowther, 1992).

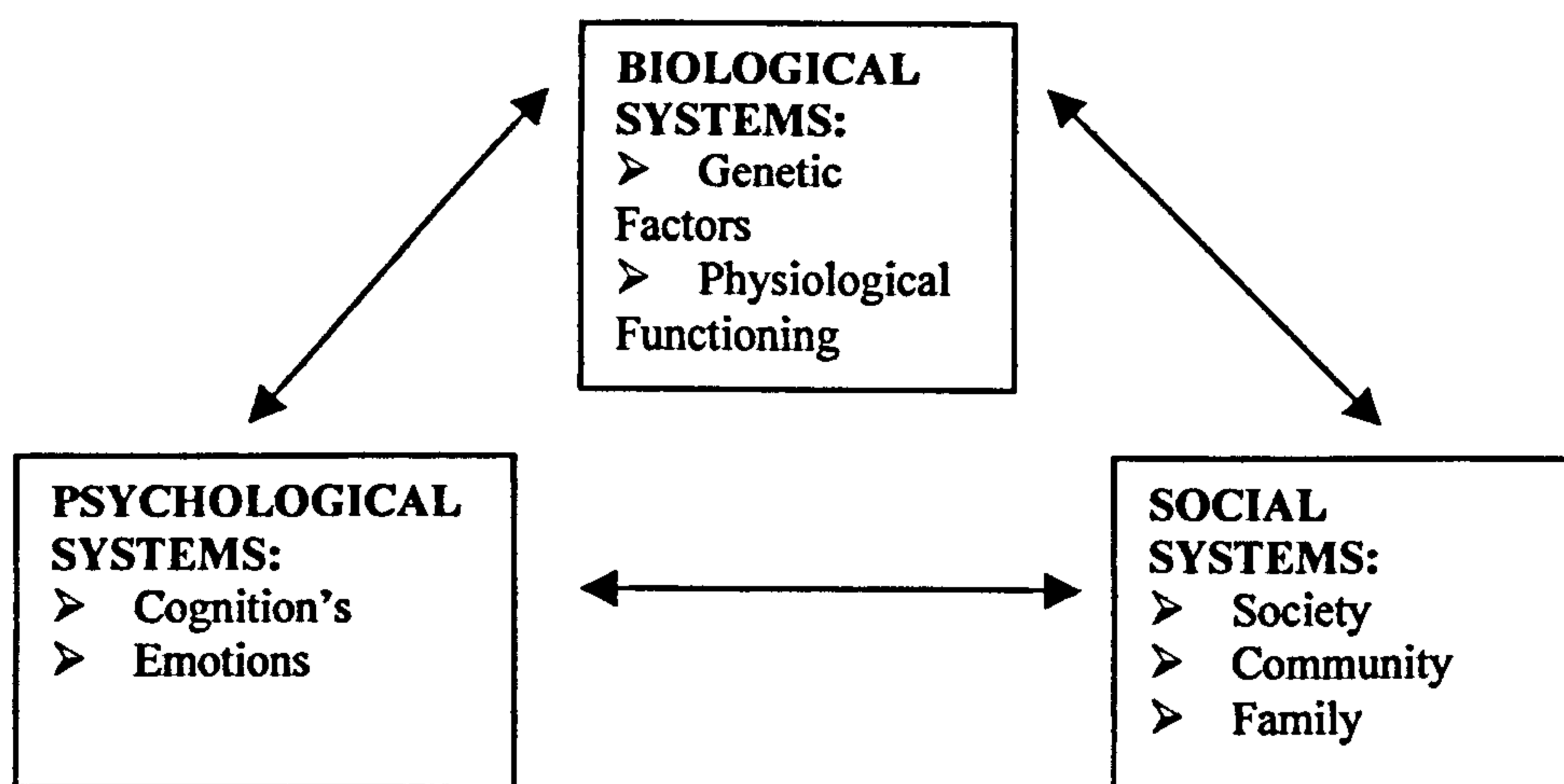
Models in adult health psychology which include the influence of the family on health and adjustment will be discussed below.

The Biopsychosocial Model (Engel, 1977)

The biopsychosocial model, also known as 'The holistic model', could be argued to be the foundation model of health psychology. The biopsychosocial model is a

systemic framework that attempts to explain all the factors that can contribute to illness, recovery, adjustment and so on. It argues that all the factors inter-relate with each other resulting in illness expression. The strength of the model lies in its ability to explain why two individuals with the same illness type and illness severity can have very different responses to illness, as well as differing illness duration, courses, recovery and so on. It recognises the usefulness and validity of the biomedical model but also argues that other systems as well as the biological must play a role in illness. These other systems are; psychological and social systems. Figure 1 illustrates the biopsychosocial model.

Figure 1: The Biopsychosocial model (Engel, 1977)



Adapted from: Sarafino (1998)

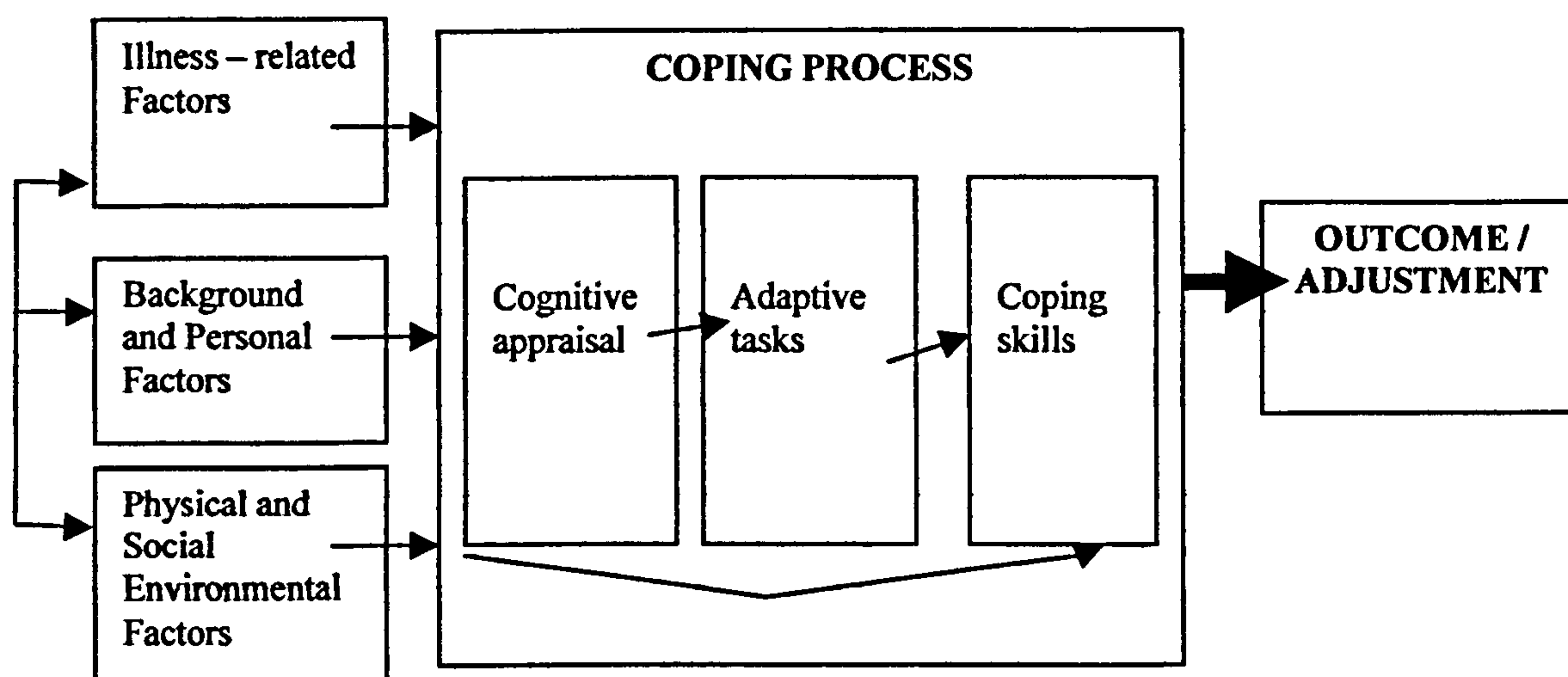
Disruption in any one of these systems will result in a knock-on effect in the other systems, therefore further enhancing the idea that these three systems are interconnected. For example, a dysfunction at an organ level can impact on the patients' relationship with his/her family and likewise the functioning of the family can impact on the course the illness takes.

The biopsychosocial model recognises the role of the family in illness. However despite this, mention of families or relatives in adult health psychology texts is scant.

Crisis Theory

Crisis theory was proposed by Moos (1982) to explain the variance in how people respond and adjust to a crisis such as chronic illness. Figure 2 illustrates the theory.

Figure 2: Crisis Theory (Moos, 1982)



From: Sarafino (1998)

This model argues that a persons illness related factors, background and personal factors, and physical and social environmental factors act together to exert an influence over the coping process which the patient engages in. This in turn influences the patients’ adjustment. Of interest for the purpose of this study is the role of the individuals physical and social environmental factor. Within the patients’ social environment, Moos discusses the patients’ family and the influence of social support on adjustment within a systemic framework. The patients’ quality of family relationships and social supports is said to combine with the other two factors to influence the types of coping used by the patient, in turn affecting outcome. In

Sarafino's (1998) description of the model he comments that the ways in which each individual in the family system adjusts to the illness will affect each others adjustment also. This is an attractive feature as it incorporates a systemic approach and allows for the relatives adjustment also to be considered. However the model does focus on the coping process as being central to the adjustment outcome and as is evidenced in figure 2 there is no direct link argued between the physical and social environment factors and adjustment.

SOCIAL SUPPORT MODELS

Social support is defined as ' the perception that others are responsive and receptive to one's needs' (Aronson, Wilson and Akert, 1997).

Research in to stress and its impact on illness has led researchers to investigate the role of social support as a psychosocial modifier of stress. As part of this research the impact of social support on health outcome has been researched (DiMatteo and Hays, 1981). The family are recognised as the most immediate source of social support (Sarafino, 1998; Danielson, Hamel-Bissel and Winstead-Fry, 1993) and therefore models and research in this area will be reviewed.

The following theories of social support will be discussed for the purpose of this review. They are; the buffering hypothesis, the main effects hypothesis and the perceived social support model.

The Buffering Hypothesis

Cohen and Wills (1985) proposed that social support acts as a buffer in the relationship between stress and illness. There are two pathways in which this buffering may operate. The perception of supportive others may influence peoples' interpretations of events as stressful. Therefore they may appraise the event as not exceeding their realms of coping, as others will help with this coping. In this way, social support intervenes to prevent events from being perceived as stressful. If the event is appraised as stressful the influence of the supportive others can reduce the impact of this stress by providing help, assistance and promoting problem solving behaviours. Therefore social support reduces the harmful effects of the stress by provision of additional coping resources.

The Main Effects Hypothesis

Rather than viewing social support as having an intermediary effect, this hypothesis suggests that social support has a direct effect on stress and illness. Cohen and Wills (1985) argue that social support promotes positive well-being in an individual which prevents the occurrence of negative events. As the presence of social support relates to well-being, so does its absence relate to poor well-being.

Perceived Social Support Model

This model emphasises that the impact of social support on health is determined by the recipients interpretation of its usefulness. Therefore an individual can have many social contacts but perceive them all as ineffective. In this example the individual is unlikely to seek supportive behaviours and the presence of social supports will be rendered useless and will not act as a protective mechanism. Therefore, we should be

considering the perceived quality of social support as well as its presence and frequency.

RESEARCH EXAMINING THE IMPACT OF SOCIAL SUPPORT ON ADJUSTMENT

Social support has received a great deal of interest as an explanation of the variance in response to illness. There are a multitude of studies examining its influence on illness onset, course and recovery (Reifman, 1995; Berkman, 2000). For the purpose of this review only studies examining the impact of social support on psychological adjustment will be reviewed.

Social support has been found to serve as a protective factor in psychological adjustment to cancer (Armstrong, 2001), coronary heart disease (Drewniak, 2001), melanoma patients (Soellner, Zschocke, Zing-Schir, Stein, Rumpold, Frish, & Augustin, 1999), chronically ill adolescents (Peterson, 1998), breast cancer (Steele, 1998), and diabetes (White, Richter & Fry, 1992; Littlefield, Rodin, Murray, & Craven 1990). Intervention studies amongst those recovering from a physical illness have provided evidence of the protective nature of a supportive environment against psychological maladjustment (Gruen, 1975; Spiegel, Bloom & Gottheil, 1981). Given that family are the patients naturally occurring and most readily available source of social support, the importance of studying families influence in adjustment is paramount. If the patient perceives the social support they receive as desirable and useful it can have a powerful influence over their psychological adjustment to illness.

Grossman (1995) examined received support and psychological adjustment in critically injured patients and their families. This study is somewhat unique in that it examines both the patient and family members' psychological adjustment and support behaviour and looks at how one influences the other. Psychological adjustment was assessed using the state-trait anxiety sub-scales (Spielberger, 1987) and the well-being scale (Schlosser, 1990). Their findings lend support to the notion that relatives' psychological adjustment can influence the patients' own adjustment and vice versa.

If the relationships from which the patient receives support are negative or the families functioning is dysfunctional, then the impact of social support on adjustment can be detrimental. The negative effects of social support have also been investigated, although to a lesser extent. The majority of research in to the negative impact of social support tends to focus on health outcome when social support is lacking. For example those who are isolated have been found to have increased chances of dying prematurely (Berkman and Syme, 1979).

Those studies of psychological adjustment have shown that negative interactions within social supports are more strongly related to psychological adjustment than are positive interactions (Rook, 1984). Such findings of the influence of negative interactions of social support have led researchers to investigate the concept of social support further than the patients' perception of available and useful support. The social support construct has received criticism in the literature (Pistrang and Barker, 1995), as simply knowing that the patient perceives the support as useful or unhelpful, tells us little about the processes which occur in these supportive relationships, therefore providing little helpful information for designing interventions. Social

support literature has therefore moved towards defining these relationships in such a way that they will prove useful for intervention purposes. Study of the family environment, quality of family relationships and family functioning have been investigated.

The patients' family functioning was the area of interest for the present research. Family functioning theory will now be discussed. This will be followed by discussion of the research which has examined the role of family factors in individuals' psychological adjustment to illness.

FAMILY FUNCTIONING THEORY

In the present study the ill persons family will be viewed as their social support. This decision was made because the patient spends a period of time after ITU/Cardiac surgery at home 'recovering'. During this time it is typically the relative who provides the main source of care for the patient. It was therefore felt that examining the quality of the families functioning would provide a measure of the context in which patients are receiving their support. Therefore family functioning would be indicative of social support and could be argued to impact on adjustment.

Family functioning refers to the behaviours and patterns of interaction of a family. There are several models of family functioning including; the structural model (Minuchin, 1974), strategic models (Haley, 1976), The McMaster model of family functioning (Epstein, Bishop and Levin, 1978), The Circumplex model (Olson, 2000), and The Beavers and Hampsons' model (1990). The chosen model for the present

research was the McMaster model (Epstein et al., 1978) which will now be described below. This model was chosen because of the following reasons:

- The model is derived from clinical theories.
- The model was constructed from the findings of a large (1,100 families) empirical study of non-clinical families (The Silent Majority - Westley and Epstein, 1969). Initial constructions of the model were tested in clinical work and research and revised.
- A self-report assessment tool has been devised from the model which is easy to administer, having practical attractions for research purposes.
- It contains several domains of family functioning. This allows researchers / clinicians to ascertain certain areas of functioning which may be problematic for families and target interventions by helping families move towards what the model advocates as more healthy functioning.
- It allows families to be classified along a continuum of healthy to non-healthy families. The higher the score the more unhealthy the families functioning.
- The model focuses on the aspects of family functioning which are believed to have most significance on problem areas of individual members such as psychological distress, and ill-health.

A criticism of the McMaster model is its use of the terms healthy and unhealthy.

These could be viewed as terms that pathologise families. Although these terms have been adopted for the use of the current project, in line with the literature, the intention is not to suggest that there is some fault in the family that led to psychological difficulties. Families with 'unhealthy functioning' were viewed as having difficulties adjusting to the demands created by the presence of serious illness.

The McMaster Model of Family Functioning (Epstein et al., 1978)

The original conceptualisations of the McMaster model (Epstein, et al., 1978) were constructed from the findings of a large (1,100 families) empirical study of non-clinical families (The Silent Majority - Westley and Epstein, 1969). Since then the model has been tested in clinical, research and teaching settings and has been revised and updated in accordance with findings. The research group thus argue that 'The result of this pattern of development has been that the model is pragmatic' (Miller, Ryan, Keitner, Bishop & Epstein, 2000, p. 169).

The McMaster model of family functioning (Epstein et al., 1978) has its theoretical roots in systems theory (Miller et al., 2000). Epstein, Bishop, Ryan, Miller and Keitner (1993) summarise the aspects of systems theory which constitute their model as:

1. The parts of the family are interrelated
2. One part of the family cannot be understood in isolation from the rest of the system
3. Family functioning cannot be fully understood by simply understanding each of the parts
4. A family's structure and organisation are important factors determining the behaviour of family members
5. Transactional patterns of the family system are among the most important variables that shape the behaviour of family members. (Epstein et al., 1993, p. 140)

The McMaster model advocates that the main purpose of the family is to provide it's members with the foundations for optimal development. They argue that this development occurs on three levels; biological, psychological and social. In the families journey towards optimal development they will need to negotiate a number of

tasks. Three main task areas are identified in the McMaster model. They are; the basic task area, the developmental task area and the hazardous task area. Basic tasks encompass provision of life's essentials, such as money, food and shelter. The developmental task area refers to the tasks both the individual and the family have to negotiate through their life cycles. Examples of developmental tasks that a family may have to negotiate are; the adjusting of parent-child relationships which occurs as a child reaches adolescence and takes on more autonomy (Carter and McGoldrick, 1989). On an individual level, different tasks will need to be negotiated at middle childhood, than say later life (Newman and Newman, 1991). The lifecycle stage of the family and the individuals is therefore an important consideration in our thinking about family's functioning. The hazardous tasks area refers to how families manage crises, for example; illness and loss. The premise of the model is that if families have difficulty in negotiating these main areas they will not be functioning optimally and it is then that problems will arise. Families who function optimally are classified as 'healthy' and those who are not functioning optimally are classified as 'unhealthy'. Applied to the current research, if families have difficulties negotiating these main task areas their adjustment to illness will be problematic.

The McMaster model postulates that there are six dimensions which conceptualise a family's functioning. If functioning in these domains are healthy, families will be able to successfully negotiate the three main areas described above. The six dimensions are: problem solving, communication, roles, affective responsiveness, affective involvement, and behaviour control.

The following will briefly describe the main concepts of each domain and Epstein and Bishop's (1981) postulated most effective and least effective characteristics.

PROBLEM SOLVING

Epstein and Bishop (1981) divide problems into two types; instrumental and affective. Instrumental refers to problems which are of a more day to day practical nature, such as managing finances. Affective refers to problems involving feelings. They describe the problem solving process in 7 stages. First the family must identify what the problem is (1). Then they need to communicate that the problem is present (2). They then need to consider different ways to solve the problem (3). After consideration they need to decide which method they will adopt (4) and then they need to act on this decision (5). The family must then monitor their action (6) and finally evaluate its success (7).

Epstein and Bishop (1981) postulate that problem solving is most effective when all seven of these stages have been engaged in, and least effective when the family is unable to identify the problem.

COMMUNICATION

Again there are the two types; communication about 'practical' matters (instrumental) and communication in relation to feelings (affective). They describe four types of communication styles; clear and direct, clear and indirect, masked and direct, masked and indirect. The most effective is argued to be clear and direct, and least effective; masked and indirect.

ROLES

This has been defined as “the repetitive patterns of behaviour by which family members fulfil their family functions” (Epstein et al., 1993). This dimension relates back to how the family allocates responsibility to its members to help the family acquire the three main task areas which underlie the model (basic, developmental and hazardous task areas). It also addresses how the family monitors if these functions are being carried out.

Healthy functioning is characterised as families who accomplish the main task areas by allocating family members roles and doing this with a sense of accountability, while at the same time sharing tasks out amongst the family, rather than one person becoming over burdened. Epstein et al (1993) also state that each member should be clear about what their role is.

AFFECTIVE RESPONSIVENESS

Affective responsiveness is defined by the McMaster model as; “the ability to respond to a given stimulus with the appropriate quality and quantity of feelings” (Epstein et al., 1993, p.149).

The quality of affective response is further divided in to family members’ ability to experience the full range of human emotions and whether the emotions expressed are both stimulus and situationally coherent.

The quantity of feelings expressed in the definition refers to the degree of emotional response expressed. This is viewed along a continuum from those who display an

absence of emotional response to those who display excessive emotional responsiveness.

They also distinguish between 'welfare emotions' and 'emergency emotions'.

Examples given of welfare emotions are; happiness, warmth, tenderness, support.

Emergency emotions are; anger, sadness, depression.

Healthy families are conceptualised as being capable of expressing a full range of emotions which are considered to be appropriate for the occasion and of appropriate intensity.

AFFECTIVE INVOLVEMENT

This relates to the degree of interest which family members take in each other. The McMaster model describes six types of involvement displayed by individuals. They are :

1. **Lack of involvement:** no interest or involvement in one another.
2. **Involvement with absence of feelings.**
3. **Narcissistic involvement:** interest in others only when the behaviour has a direct reflection on their own behaviour or interests.
4. **Empathic involvement:** interest displayed for the sake of the others (selfless).
5. **Overinvolvement:** involvement which would be considered to be excessive.
6. **Symbiotic involvement:** pathological interest in one another which presents as difficulty in differentiating one individual from another. (Epstein et al., 1993, p.151).

Empathic involvement is considered to be the most healthy type of involvement.

BEHAVIOUR CONTROL

This dimension describes the typical patterns of behaviour a family adopts in its attempts to manage situations which are; dangerous, require the family to address and express psycho-biological needs and situations which involve social interactions. The styles of behaviour control described below (Epstein et al., 1993) reflect the family's standards for acceptable/non-acceptable behaviour and the rigidity/flexibility of these standards. They describe four types of behaviour control which are:

1. **Rigid behaviour control.** Here the standards are very tightly defined and there is little room allowed for acting outside of these standards.
2. **Flexible behaviour control.** The standards which are set are regarded as reasonable and there is latitude for negotiating.
3. **Laissez-faire behaviour control.** No standards are set and individuals have a free rein to set their own standards for situations.
4. **Chaotic behaviour control.** The family will shift from one style of behaving to another with no predictability. Individuals have no frame of reference about what standards apply and how much latitude they have.

The model states that flexible behaviour control is the most adaptive and chaotic behaviour control is the least adaptive.

RESEARCH RELATING TO THE IMPACT OF FAMILY FUNCTIONING AND FAMILY FACTORS ON PSYCHOLOGICAL ADJUSTMENT TO ILLNESS

It is important to say here that a review of the research on families and illness appears at the outset to be quite promising. Much of this literature, however, involves an examination of the impact of illness on the family system and has in the large occurred in the child literature which will not be reviewed here. This type of research is a separate question to that which is hoping to be addressed in the current research i.e. the impact of family factors on individuals' adjustment. However research in to the impact of illness on the family system has produced a wealth of research and a proliferation of models. The following section will therefore touch on one of these models as it has interesting implications which aided in the design of the current project. This current section will review those research papers which have examined the role of family factors on individuals' psychological adjustment to illness.

As with the social support literature, once studies are narrowed down to those considering psychological adjustment to illness, few articles are left remaining. This is in many ways surprising when you consider the findings that report health status is not a good predictor of psychological adjustment (Grossman, 1995; Arpin et al., 1990). Such findings have led researchers to question what the variables must be that account for variance in psychological adjustment. It would appear from surveying the literature that the focus of this research is the influence of individual variables such as coping, illness representations etc. The lack of interest in researching the influence of

family factors amongst adult populations is surprising when you consider the importance of the family within the social system of the biopsychosocial model.

The lack of research in to the role of the family in psychological adjustment to illness is apparent in Campbell's (1986) critical review of research pertaining to family's impact on health. In this review Campbell discusses research in physical health and selected reference to the mental health field. He covers; cardiovascular disease and hypertension, diabetes, asthma, pregnancy, compliance and obesity. All of the research reviewed covers the impact of the family on the development or course of these illnesses. Therefore, as has been the recurrent pattern in the social support literature the focus is on the relationship to health status or severity.

Throughout this review there is no mention of psychological adjustment to illness.

This is maybe not surprising given the fact that the review was conducted in 1986 and the development of models such as Crisis theory, which attempts to explain the variance in psychological adjustment, was not developed until 1982. Therefore, around the time Campbell's (1986) review article was being written, ideas and research about psychological adjustment to illness were just beginning to be developed.

Despite the lack of reference to psychological adjustment, this review paper includes some very useful criticism of family and health/illness research and recommendations for future research. Campbell makes reference to the preponderance of uni-directional research and recommends that future research should consider multi-directional relationships. He discusses how multi-directional research is more difficult but makes

reference to systems theorists who argue that attempting to establish causality is a meaningless and impossible task. Campbell also criticises the methodology of the research. He recommends that comparison groups be used which make use of 'normal' families with an absence of illness as well as using other chronic illness groups. Campbell also discusses how confounding variables should be controlled for in family studies by using matching or statistical analyses. He discusses that the important variables to be controlled for are; "age of patient and stage of the family life cycle, socio-economic status, severity, length and stage of illness and psychological health of the individual patient".

Since Campbell's paper a body of literature has formed which recognises the needs of the family and the role of family factors on psychological adjustment to illness. This will now be discussed.

Arpin et al. (1990) investigated the prevalence and relationship of family functioning and cognitive appraisal to psychosocial adjustment across illness specialities. They hypothesised that the type and severity of illness would be unrelated to psychosocial adjustment but that family functioning and cognitive appraisal would be related to adjustment. They also hypothesised that these relationships would not differ across specialities. They recruited 216 participants from the three major speciality clinics of mixed cancer, gastroenterology and rheumatology. Family functioning was assessed using the Family Assessment Device (FAD) (Epstein, Baldwin and Bishop, 1983). Psychosocial adjustment was assessed using the Psychosocial Adjustment to Illness Scale (PAIS-SR) (Derogatis & Lopez, 1983). Resulting correlations between family functioning and psychological distress ranged from 0.18 to 0.38. Combining family

functioning and cognitive appraisal, while adjusting for disease and severity variables, accounted for 0.57 of the variance. Although the variance of adjustment accounted for by family functioning alone was a relatively small correlation, Arpin et al. (1990) stress that these variables account for more of the variance than disease variables which only accounted for 7% of the variance. As was hypothesised differences across medical specialities was not significant in any of the areas of family functioning, cognitive appraisal or adjustment. Thirty per cent of the sample displayed unhealthy levels of family functioning. This study is hugely important for establishing the potential role of family functioning in psychological adjustment to illness and for laying down initial foundations for future research. In this study the patient completed all of the measures and at no point were any other family members interviewed. Incorporating the perspective of the relatives who provide the patients support and investigating their view of family functioning and their psychological adjustment to illness would allow for a more systemic analysis of psychological adjustment.

Groom, Shaw, O'Connor, Howard and Pickens (1998) also utilised the FAD and found that family functioning was strongly related to depression in traumatically brain-injured adults.

Brown, Rawlinson & Hardin (1982) have also addressed the relationship between family functioning and psychological adjustment in their study with coronary artery disease patients. They hypothesised that poorer family functioning, measured using the Family Functioning Index (Pless and Satterwhite (1973), would be related to poorer psychological adjustment, using the Minnesota Multiphasic Personality Inventory scales of hypochondriasis, depression, hysteria, and Welsh's anxiety scale.

With the exception of a significant negative relationship between adequacy of family functioning and anxiety, no significant relationships were reported.

An interesting aspect of Brown et al's (1982) discussion is that they recommend future research should take account of the stage of the family life cycle which families are at when their family member becomes ill. This recommendation for future research has been echoed throughout the research (Campbell, 1986) and is also a strong component of Rolland's Family System Illness Model (1993) which will be discussed in the following chapter.

Research examining the role of partner criticism in patients' psychological adjustment has also been addressed, with interesting findings. Manne and Zautura (1989) examined the relationship between spouse criticism, methods of coping and the patients' psychological adjustment, amongst 103 patients with rheumatoid arthritis and their spouse. They developed and tested a linear model which hypothesised that feelings of personal vulnerability to illness would influence the spouses interaction with the patient. This interaction would be expressed as either positive support or as critical comments. The model then proposed that critical comments would influence the patients' coping towards an unhelpful style of coping which would lead to poor psychological adjustment. On the other hand, the patient with the supportive spouse would be more likely to engage in positive ways of coping and this would in turn result in better psychological adjustment. Spouses completed measures of vulnerability to illness and a measure of 'burden'. They also completed an interview from which critical comments were measured. Patients completed measures of illness

severity, activity limitation, coping, positive social support and psychological adjustment.

Findings provided support for the hypothesis that spouse criticism would indirectly influence psychological adjustment through influencing the types of coping utilised by the patient. This research can be criticised for its unilinear model. It does not take account of the spouses psychological adjustment to the illness and the bi-directional (circular) influences this will have on the patients' coping and adjustment. The measure of psychological adjustment employed in this measure was the Mental Health Inventory (Veit and Ware, 1983). This measure was chosen as it is a good measure of psychological adjustment in the general population, rather than having its norms taken from a psychiatric population. This measure will not take account of the physical symptoms which chronically ill patients report that elevate scores on traditional measures of psychological adjustment. The use of a measure such as the HADS would have ameliorated the possibilities of "false" elevated scores of psychological distress.

However this is an important study and its strengths lie in the large numbers of participants recruited and the clear rationale laid out in its model. As is echoed by the authors of this research, their findings are the first to highlight the association between critical remarks and psychological adjustment in the chronically physically ill population.

Research with multiple sclerosis patients has also revealed the negative impact of spouse criticism on patients' mental health and the positive effects of spouse encouragement (Schwartz and Kraft, 1999).

There is also a body of literature which establishes the relationship between family factors other than family functioning (i.e. family relationships, social environment and marital functioning) and patients' psychological adjustment. This relationship has been reported across a number of illness specialities. Examples include; cancer (Rodrigue & Park, 1996; Pistrang and Barker, 1995; Friedman, Baer, Nelson, Lane, Smith & Dworkin, 1988; Spiegel et al., 1983), end-stage renal dialysis (Christenson, Turner, Slaughter & Holman, 1989); cardiac patients (Sykes, Hanley, Boyle, Higginson & Wilson, 1999), myocardial infarction (Mayou, Foster and Williamson, 1978), long-term survivors of bone marrow transplant (Molassiotis, van den Akker and Boughton, 1997) and traumatic brain injury (Landsman, Baum, Arnkoff, Craig, Lynch, Copes and Champion, 1990) .

It is apparent then that a small body of research pertaining to the influence of family functioning and family factors on psychological adjustment exists. However the differing types of family factors measured (i.e. family functioning, family environment, social environment, social support, critical remarks and marital quality) and differing tools to measure psychological adjustment does make comparison of results difficult. The studies described above also only make reference to the patients' adjustment. They do not include how the relative adjusts to the illness, the role of family factors in relatives' adjustment, or explore the possible relationship which may exist between patients' and relatives' adjustment. Future research will need to apply

more of a systemic nature to its design. Systemic designs are more in accordance with theories such as the biopsychosocial model. If future research can achieve these goals it will help towards providing patients and their family's with a more holistic form of research driven intervention.

A small body of research has begun to examine the psychological adjustment of spouses and relatives to illness. Studies with relatives of patients with other health problems such as cancer, (Kaye and Gracely, 1993; Omne-Ponten, Holmberg, Bergstrom, Sjoden and Burns, 1993; Blanchard, Albrecht and Ruckdeschel, 1997), traumatic brain injury (Groom et al., 1998), multiple sclerosis (Packenham, 2001) and severe cardiomyopathy (Bohachick and Anton, 1990) report that relatives also have elevated levels of psychological distress and that this is often comparable and in some cases greater than the psychological distress of the patient. These papers call for health professionals to address the distress of the relatives as well as the patient (O'Farrell, Murray and Hotz, 2000; Kaye, 1993). There have also been claims for future research to investigate factors which may mediate the expression of psychological distress (Blanchard et al., 1997).

Amongst this research has also been the finding that patients' and relatives' psychological adjustment are related (Northouse, Dorris & Charron-Moore, 1995). However studies also report significant differences between patients' and relatives' adjustment (Northouse, Mood, Templin, Mellon & George, 2000).

Although there is now a literature which informs us that relatives experience psychological distress, this literature is still limited in relation to its exploration of the

factors which may predict adjustment in relatives. As is evident in the above review for patients' adjustment, family factors have been found to be related to and predictive of patients' adjustment. Relationships between family factors and relatives' adjustment is however limited. In fact exploratory models to explain/predict relatives' adjustment are scant. Northouse et al (2000) suggest that spouses may not express their need for support and that "others (including professionals) perceive of spouses as caregivers rather than care recipients" (Northouse et al., 2000, p. 281). These attitudes and perceptions may be reflective of the continued dominance of the medical model which focuses intervention on the physical recovery of the patient, often at the expense of the relative. More widely there may also be a cultural tendency for a focus on the patient. This is evident in peoples enquiries in to patients well-being and implicit assumptions that relatives adopt the role of 'carer'. These cultural and medical model driven assumptions may explain why the psychological needs of family members in adult physical health services are given such low priority, both in research and in clinical practice.

The research that has been carried out has tended to report that the factors which predict adjustment in patients and relatives/spouses are often different (Northouse et. al., 2000; Northouse, Dorris & Charron-Moore, 1995; Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; and Purden, 1995). Northouse, Dorris & Charron-Moore (1995) investigated factors which relate to couples' adjustment to recurrent breast cancer. They found that personal support was significantly related to psychological distress in the women (patients) but that it was not significantly related for the spouses. Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris (1995) carried out a study with 300 women and their partners prior to breast biopsy. Amongst

the women (patients) there was no significant relationship reported between family functioning and psychological distress. However for the partners, family functioning was a significant predictor of psychological distress. High predictors of psychological distress for the patients in this study were lower education and uncertainty. Another study examining adjustment two months post-myocardial infarction (Purden, 1995), found that for husbands (patients), clinical factors were best at predicting adjustment, whereas for the wives both clinical and psychosocial factors were the most important predictors of adjustment. Another study with female spouses of cardiac rehabilitation patients (O'Farell and Murray, 2000) found a significant relationship between poorer family functioning and psychological distress. Examination of these studies suggests that there does not appear to be any gender basis in determining the importance of family factors on adjustment. Both men and women in the above studies reported family functioning was related to adjustment. It seems more likely that the role of relative is a better determinant of the relationship between family functioning and adjustment with the majority of the above studies reporting this relationship in relatives.

In the majority of these studies family functioning and family factors have been found to be an important predictor of psychological adjustment in the relatives of ill patients. These studies suggest that further research examining explanatory models of adjustment in relatives of ill members is needed. It may be that different models of adjustment are indicated for patient and relative.

As is evident then from the studies discussed above, research investigating the role of the family in psychological adjustment to illness is still an area in its infancy. That

which has been investigated has produced a mixture of results, but the majority tends to point towards family factors playing an important role in adjustment. Measures used for both family functioning and psychological adjustment have been varied making comparisons difficult. It would therefore seem that there is still a great deal of research to be done to address the significance of family factors in psychological adjustment of both patients and relatives. If families with an ill member do have difficulties in their functioning and this is impacting on psychological adjustment, this is clearly a targetable area for future intervention at a family level.

A general criticism of the individual health psychology research is the uni-linear causality applied, despite the systemic nature of the biopsychosocial model. For example, much of the social support and family functioning research discussed above examines the impact of the patients' perceived social support/family functioning on the patients' adjustment to illness. Research focusing on the relatives' adjustment to illness is in the minority and there has been little attempt to provide explanatory models for their adjustment. Consideration of how the patients' adjustment will impact on the relatives' adjustment or vice versa is another area where little research has been carried out. Studies have also assumed the direction of causality, reporting their findings as indicative of family factors influencing adjustment. It is of course possible that a patient or relatives' adjustment may also be causing changes in the family functioning. It is possible to consider that the causality may be multi-directional. Clinical interviews could provide the additional information to establish if poor family functioning existed prior to illness. Such clarification would 'fine-tune' interventions. It can be argued that in order better to understand illness and how individuals adjust we need to be thinking that the pathways of adjustment involve

multi-directional causality, therefore employing more of a systemic model to the patients' and relatives' adjustment.

Systemic models of illness are abundant in the family health psychology literature. This body of literature focuses on the impact of illness on the family system and the impact of the family system on the illness. Adjustment in family health psychology refers to how the family as a whole adjust to illness. It is therefore different from individual health psychology which focuses on the impact of variables to the individual patients' adjustment.

SECTION III

FAMILY HEALTH PSYCHOLOGY INFLUENCES

This section will briefly describe a family health psychology model which had influence over the design of the current research project. This is Rolland's Family System Illness Model (1993)

Rolland's Family System Illness Model (1993) attempts to provide a framework by which we can understand families coping and adaptation to illness. It explains how family and illness factors combine to impact on optimal coping and adjustment. It is a systemic and developmental model, focusing on the family system and illness-family interactions over time. Rolland presents a three-dimensional model whereby illness type, time phases of the illness and family system variables interact to account for the family systems' adjustment. Each of these three components will now be briefly discussed.

Illness Type – Rolland has classified illnesses according to the psychosocial demands they place on the family. This has been achieved by paying careful attention to the onset, course, outcome and incapacitation of illnesses. They result in the classifications of fatal, shortened life span – possible fatal, and non-fatal. Different psychosocial demands will be placed on the family according to illness type and will therefore be a contributing factor to their overall adjustment.

Time phases of illness – This is divided into the phases of; crisis, chronic and terminal and Rolland advocates that different phases will place different demands and poses different tasks on the family and must therefore be taken into account.

Family System Variables – Rolland has highlighted the following as important variables which influence a family's coping with illness. The family's previous experiences with illness, loss and crisis is argued to influence how they will cope with the present threat. The model also emphasises the role of life-cycle frameworks, in particular the interplay of the individual life cycle with the family life cycle and the illness life-cycle. So for example a family with young children whose ill family member is in their late twenties and has just received a diagnosis will have to negotiate different tasks and have different demands to a family in their later stages of life who are attempting to negotiate a chronic illness. Consideration of all three of these life cycles and their interaction will influence the way the family reacts and copes with the illness. The other family system variable centres around health and illness beliefs held by the family. These will determine how they perceive and understand the illness and will impact on their behaviour and adjustment.

Finally, the combination of all three of these dimensions and their subsequent interactions will influence how the family adapts and adjusts to illness.

Consideration of the stage of family life cycle and the families previous experiences with illness were combined into the design of the present study.

SECTION IV

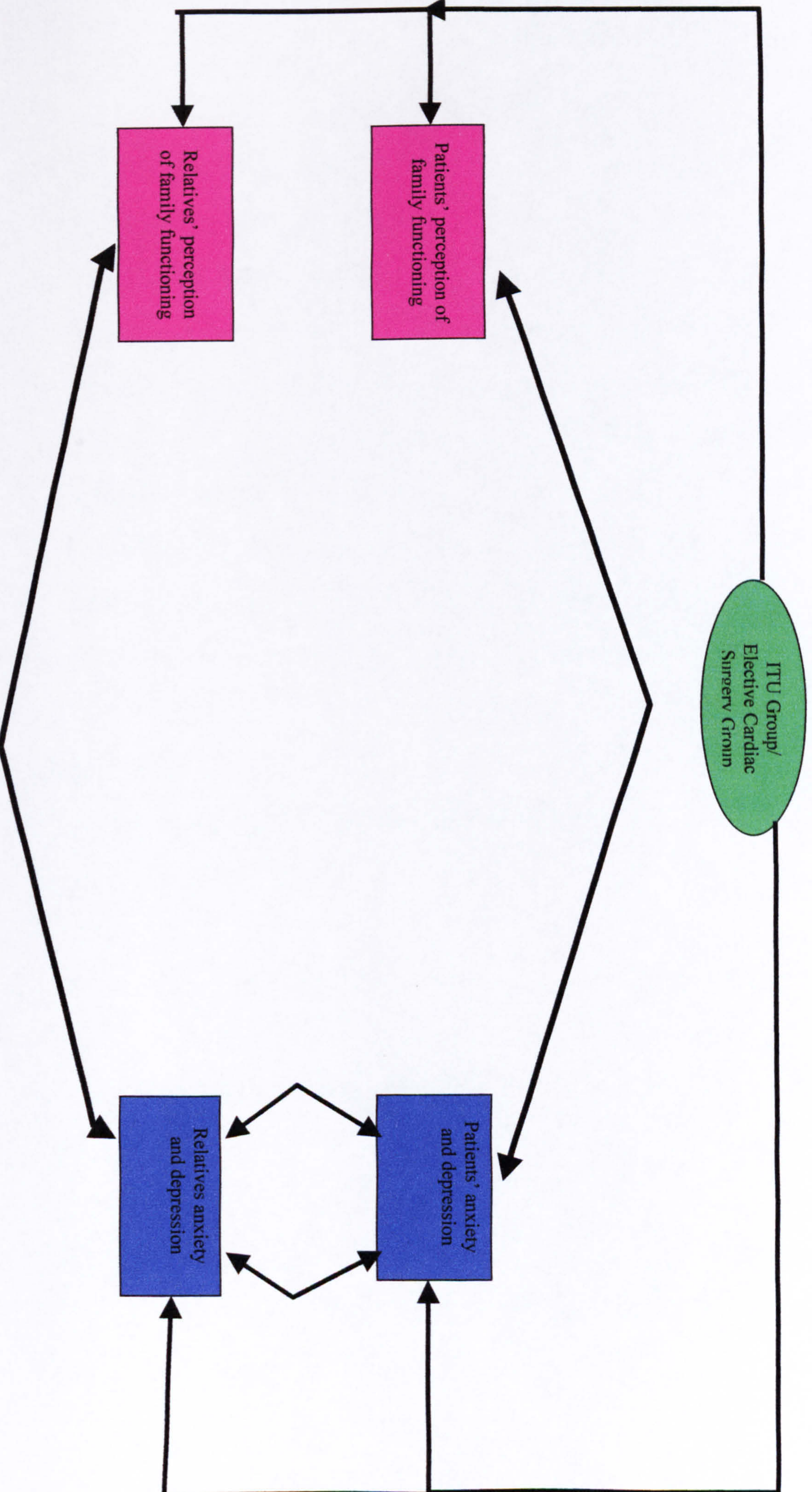
RESEARCH MODEL

Campbell's (1986) criticisms of the lack of a comparison group, and the claims within the ITU literature that these patients may be a 'unique' population, led to the decision to include a comparison group in the design. An elective cardiac surgery group were used as a comparison. Justifications for using this group are discussed in the design section.

The research model is presented below in Figure 3. It was hoped that the factors presented in the model would address the criticisms that previous research has focused primarily on the adjustment of the patient and has not considered the relatives' adjustment or the relationships which may exist between patient and relative. The research model attempts to explain the variance in patients' and relatives' adjustment by consideration of family factors, while keeping in mind that adjustment may also be explaining the variance in family functioning. The relationship between perceived family functioning and adjustment and the relationship between patients' and relatives' adjustment was therefore investigated in a bi-directional manner.

As well as consideration of the role of family factors in adjustment, the model also incorporates the possible contribution of being an ITU or cardiac patient to adjustment. The first two research questions can therefore be summarised diagrammatically by the model.

FIGURE 3: RESEARCH MODEL



RESEARCH QUESTIONS

The current study aimed to address four questions which were derived from the literature review of psychological problems in ITU. These were:

- 1. Are ITU patients and their relatives a ‘unique’ sample?**
- 2. What influence do family factors (family functioning and each others adjustment) have on psychological adjustment of patient and relative?**
- 3. Do any of the research models factors explain a significant amount of the variance in psychological adjustment/family functioning?**
- 4. Do patients and relatives differ in their recollections of ITU illness severity and does this difference impact on psychological adjustment?**

The following hypotheses were designed to answer these questions.

HYPOTHESES

Are ITU Patients and Their Relatives A ‘unique’ Sample ?

GROUP DIFFERENCES:

Hypothesis A:

There will be no significant difference between the ITU group (patients and relatives) and the elective cardiac surgery group (patients and relatives) on measures of psychological adjustment (as measured by anxiety and depression scores of the HADS).

Hypothesis B:

There will be no significant difference between the ITU group (patients and relatives) and the elective cardiac surgery group (patients and relatives) on perceived family functioning.

OPEN QUESTION

**WHAT COMES TO MIND WHEN YOU THINK OF LIFE BEFORE ITU/
ELECTIVE CARDIAC SURGERY AND NOW?**

- 1. What are the main themes that emerge in the ITU and elective cardiac group?**
- 2. Do the themes between the two groups appear to be qualitatively different?**

The Relationship Between Family Factors And Psychological Adjustment

In The ITU Group:

The McMaster model predicts that as family functioning becomes more unhealthy so too will psychological functioning become more unhealthy. This predicts a positive relationship between the two factors which has been supported by research findings (Groom et al., 1998 and Arpin et al., 1990). Based on these findings, a one-tailed test was therefore chosen to test hypothesis C below. However a positive relationship does not assume causality and a systemic understanding can still be applied to these analyses.

Hypothesis C:

There will be a significant positive relationship between family functioning scores and psychological adjustment (as measured by anxiety and depression on the HADS) in patients and relatives.

Hypothesis D:

There will be a significant relationship between patients' and relatives' psychological adjustment.

The Relationship Between Family Factors And Psychological Adjustment

Within The Elective Cardiac Surgery Group:

Hypothesis C:

There will be a significant positive relationship between family functioning scores and psychological adjustment (as measured by anxiety and depression on the HADS) in patients and relatives.

Hypothesis D:

There will be a significant relationship between patients' and relatives' psychological adjustment.

RESEARCH MODEL QUESTIONS

1. Do any of the models factors contribute significantly to the variance in patients' and relatives' psychological adjustment?
2. Do any of the models' factors contribute significantly to the variance in patients' and relatives' perceived family functioning?

SPECIFIC ITU RELATED QUESTIONS?

Hypothesis E:

There will be a significant difference in patients' and relatives' perception of severity of illness while in ITU.

Hypothesis F:

There will be a significant positive relationship between the difference score of severity of illness and psychological adjustment of patients and relatives

METHOD

DESIGN

The research design was a single-measurement point matched group comparison. Two groups were used as a comparison:

1. ITU group (Quasi-experimental group)
2. Elective cardiac surgery group (Comparison group)

Manchester Royal Infirmary (MRI) was the hospital from which participants were recruited.

A comparison was used to address some of the methodological criticisms of earlier work i.e. inferences that the ITU population was a 'unique' population without the use of a comparison to back up these impressions. Clinical impressions amongst ITU workers are that the longer the patient spends in ITU, the more likely and more profound their psychological difficulties will be. However this has never been verified empirically. A criticism of family and health research (Campbell, 1986) has been the lack of control/comparison groups. A comparison group was therefore used to ascertain if ITU patients are indeed a 'unique' sample by addressing:

1. Whether or not an extended ITU stay results in greater psychological difficulties than another medical group who have experienced threat to life.
2. If ITU patients have 'unique' characteristics on the other study variables.

Elective cardiac surgery patients were chosen as the comparison group for the following reasons:

- They have experienced a threat to life through their illness and have experienced a period of critical illness post-operation. Although elective cardiac surgery patients may not experience the same degree of threat to life as an ITU population, after consultations with medical professionals it was felt that these groups were most closely matched on this dimension.
- Elective cardiac surgery patients also receive regular follow-up from the cardiac team and have a period of time after the operation when they are ‘recovering’, as do the ITU patients.
- Elective cardiac surgery patients are also a mix of patients with an acute and chronic illness history which is akin to ITU patients.

The over-riding question of this research was whether the research findings were ‘unique’ for the ITU population and therefore related to the ITU experience, or if the findings were due to other factors associated with illness. The impact of family functioning on psychological adjustment was a subsidiary area of investigation.

Elective cardiac surgery patients were matched with ITU patients on the following variables:

1. Stage of family life cycle
2. Gender
3. Previous illness history (classified as either acute illness history or chronic illness history)

These matching criteria were chosen for the following reasons.

Campbell (1986) critically reviewed the research on family’s impact on health. He recommended that future research should control for confounding variables by the use

of matching criteria. Both the stages of family life cycle and illness characteristics were mentioned as important variables for matching. The present design therefore incorporated these factors in the matching criteria (matching criteria 1 and 3).

STAGE OF FAMILY LIFE CYCLE:

It is hypothesised that the adjustment of a family, and indeed an individual will be affected by the stage of family life cycle (Campbell, 1986 and Rolland, 1993). For example, a couple who are expecting their first child will adjust differently to serious illness than a family in the later stages of life. Although illness will be difficult across the entire lifespan, it will have different repercussions for the two families mentioned in this example. Family life cycle theory (Carter and McGoldrick, 1980) is a foundation theory in family research. Participants were matched according to which stage of Carter and McGoldrick's family life cycle they belonged. Further detail of these stages can be found in the measures section.

PREVIOUS ILLNES HISTORY:

ITU patients are typically a mixture of patients with chronic and acute illness histories. Previous illness history is known to determine the already established coping skills a family brings to dealing with illness (Rolland, 1993). For example families whose relative is admitted to ITU and have never experienced the hospital system or illness in the family before may confront the experience differently to a family who have experienced numerous hospital admissions due to a chronic illness history. The family with a chronic illness history may be more prepared and have established coping skills in comparison to a family who have not had many illness experiences before. Therefore families were matched on this criteria. ITU patients

were classified as either having an acute or chronic illness history and a match was found from the elective cardiac surgery group.

Other illness characteristics were considered for matching such as illness type.

However this would not have been possible given that the elective cardiac surgery group and ITU patients contained disparate illness types. The illness characteristics of the ITU population are also extremely varied and no meaningful analysis could have been conducted. The illness characteristic of acute chronic was therefore the most meaningful characteristic to match on. It is also based on Rolland's family system illness model (1993).

GENDER:

This was chosen as a matching criteria due to research in individual health psychology which suggests males and females utilise differing coping skills (Ptacek, Smith and Zanas, 1992). There are also well known gender differences in the prevalence of anxiety and depression (Ussher, 1997). Family research has also identified gender differences in the impact of family functioning on psychological well being. Bishop, Epstein, Baldwin & Miller et al. (1988) reported that in a retired sample, male participant's health status was a greater predictor of psychological well being, whereas family functioning was a greater predictor of psychological well-being in female participants.

Figure 4 summarises the design.

FIGURE 4: SUMMARY OF DESIGN

P = Measures completed by patient **R** = Measures completed by relative

GROUP

STUDY VARIABLES:

ITU

DEMOGRAPHICS:

FAMILY FUNCTIONING

PSYCHOLOGICAL

Or

Gender

(FAD)

ADJUSTMENT

ELECTIVE CARDIAC SURGERY

Age

(P+R)

(HADS SCORES)

Occupation

(P+R)

APACHE-II scores (ITU)

Illness type

SUPPLEMENTARY QUESTIONS:

Illness History (chronic/acute)

|___(Severity of illness continuum)

|_____ |

Stage of family life cycle

Slightly ill

(P+R)

Life-threatening

MATCHED ON:

Stage of family life cycle

Previous Illness History

Gender

OPEN QUESTION: 'What comes to mind when you think of life before ITU and now?' (R)

SETTING CHARACTERISTICS

ITU's differ across the country on some of the variables mentioned below.

Characteristics of the ITU and cardiac surgery units are discussed below as a guide to allow the reader to judge the representativeness of this ITU/ heart centre sample with their own units.

Manchester Royal Infirmary (MRI) ITU

The ITU at MRI is a 13 Bedded unit with a 1:1 nurse to patient ratio. The following statistics are based on the 2001 audit information:

Number of admissions: 382

Average length of ITU stay: 11.41 days

Average APACHE-II score: 16

Average time in hospital after ITU discharge: 20.86 days

Number of direct transfers in: 33

Mortality rate: 26%

The breakdown of admitting specialities For 2001 is detailed in Table 1 below.

Table 1: The Number of Accepted Referrals per Admitting Speciality for 2001

ADMITTING SPECIALITY	NUMBER OF ACCEPTED REFERRALS IN 2001
Accident and Emergency	5
Cardiology	1
Cardiothoracic surgery	38
Endocrinology	13
ENT	6
Gastroenterology	5
General medicine	48
General surgery	73
Geriatric medicine	16
Gynaecology	8
Haematology	12
Nephrology	17
Neurology	2
Neurosurgery	20
Obstetrics	4
Oral surgery	9
Orthopaedics and trauma	11
Renal surgery	21
Renal transplant	4
Rheumatology	5
Thoracic medicine	19
Unknown	3
Urology	5
Vascular surgery	37

Follow-up Protocol:

Recovery to previous health status prior to ITU is calculated to be from 6 to 12 months post ITU discharge. At MRI patients are therefore followed up after discharge from ITU so that progress can be monitored. Once the patients' critical status has diminished they are transferred to another hospital ward for rehabilitation. While patients are on the ward they are visited by a member of the follow-up team, who monitors recovery and observes for any ITU related problems. Once the patient is considered physically well, they are discharged home to the care of their GP and family. At three months post ITU discharge patients are invited to attend a follow-up appointment at MRI which is run by the ITU follow-up team. At this appointment, physical and psychological progress is monitored through the administration of a battery of questionnaires. The questionnaires used are as follows:

- The 36 item short form (SF-36) (Ware and Sherbourne, 1992). An assessment of health status.
- The European quality of life measure (EuroQol) (EuroQol group, 1990). A health related quality of life measure.
- Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).
Used as a measure of psychological adjustment to ITU.

Patients also receive information with regards to their expected course of recovery and many problems are normalised at the follow-up appointment. Problems such as neuropathy, anxiety or physical difficulties may be detected at the follow up appointment. Referral on to the relevant speciality will be made at this point. Patients also receive phone calls from the follow up team at 6 months and a year to further check on progress.

ELECTIVE CARDIAC SURGERY PATIENTS

Heart Surgery in Manchester and the surrounding areas is provided by The Manchester Heart Centre at MRI. After surgery patients return to the cardiac surgery unit (CSU) where they typically stay overnight. If there are complications, patients will stay for longer until their condition is stabilised. The CSU is an 8-bedded unit with a 1:1 nurse to patient ratio. After CSU patients return to a high dependency area on the cardiac ward. The ward has 27 beds, and within the high dependency area there is a ratio of one nurse to every two patients. As patients recover they require less intensive nursing and the nursing ratio falls to 1 qualified nurse and 1 health care support worker for every 5 patients.

In 2001, the Manchester Heart Centre performed 1095 heart operations. This breaks down in to 824 by-pass operations, 142 valve replacements, 91 by-pass and valve replacements, 9 by-pass + other procedures (excluding valve replacements) and 29 miscellaneous.

Average length of stays for the year 2001 have been calculated as:

CSU = 1.87 days

Total hospital stay (includes CSU) = 8.4 days

The mortality rate for 2001 was 2.5%. This is calculated on the number of people who die during their hospital stay for the surgery.

Follow-up Procedures

Once patients are discharged home they are followed up by the Cardiac Liaison team. Seven days post-discharge, patients receive a routine phone-call to check progress and identify any problems. Patients also have access to a help-line manned by the Cardiac Liaison Team. The help-line is open 7 days a week from 9am until 5pm. 6 weeks after surgery patients receive a post-operative out patients appointment where they are medically assessed. If the sternum is stable patients are then given the go ahead to begin cardiac rehabilitation. All patients are offered rehabilitation, which is provided by their local health authority.

Elective cardiac surgery patients are typically able to return to work 3 months after surgery.

PARTICIPANTS

ITU Group:

Inclusion criteria: All patients who had been discharged from ITU at MRI who were due to attend the 3 month follow-up appointment and their closest relative.

Exclusion criteria:

- Living alone
- ITU stay of less than 24 hours
- Head injury
- Previous or ongoing psychiatric illness
- Under the age of 18
- Patients whose primary reason for admission was attempted suicide

Closest relative was defined as someone who was living with the patient and was most likely to be responsible for some aspect of the patients' care.

Elective Cardiac Surgery Patients (Comparison Group):

Inclusion criteria: Those elective cardiac surgery patients who match the ITU sample on the characteristics of stage of family life cycle, previous illness history and gender (for more detail of the matching procedure, see procedure).

Exclusion criteria:

- Living alone
- Previous or ongoing psychiatric illness
- Cardiac surgery unit stay of greater than 24 hours.

RECRUITMENT

Due to the follow-up appointments being 3 months after discharge from ITU it was decided to use two methods of recruitment. This would increase the number of possible patients who could be recruited for the study in the limited time that was available for data collection (November 2001– May 2002). Details of these methods across both groups are detailed below as well as the number of participants recruited by each method.

ITU Patients:

Method 1:Ward recruitment

Patients and their closest relative were approached to take part in the study after transfer to a hospital ward and before discharge to home. The nurse responsible for following up patients approached them about the study while they were on the hospital ward. The nurse briefly explained the research and gave interested patients and relatives information sheets (Appendix 1 and 2) and consent forms (Appendix 3a & b) to peruse in their own time. Patients were provided with envelopes to return consent forms in. Those patients who expressed an interest in the research were asked permission for the researcher to contact them. A contact telephone number was obtained and a contact information sheet was completed (Appendix 4). The researcher then followed up these patients by telephone.

If consent was obtained participants were sent an invitation for the research along with their appointment time for their 3 month follow up.

15 participants satisfied the inclusion and exclusion criteria and were therefore approached to take part in the study using this method. 7 (47%) participants were

recruited using this method and 8 (53%) declined to take part. Reasons for decline are unknown, as non-return of consent forms was taken as non-consent.

Method 2: Postal Recruitment

Participants were sent patient and closest relative information sheets (Appendix 5 and 6), consent forms (Appendix 3a & b) and a stamped addressed envelope along with their appointment time for the follow-up clinic. Once these consent forms were returned, the researcher telephoned the participants to gain further verbal consent and to answer any questions about the research.

30 participants satisfied the inclusion and exclusion criteria and were therefore approached to take part in the study using this method. 13 (43%) participants were recruited using this method and 17 (57%) declined to take part. Reasons for decline are unknown, as non-return of consent forms was taken as non-consent.

Many of the patients who were discharged from the ITU during the recruitment period were excluded on the basis that they were living alone. This may explain the low number of patients recruited.

Elective Cardiac Surgery Patients (Comparison Group):

All of these patients were recruited postally, although the first point of contact for the research was via a cardiac nurse. A detailed account of recruitment follows.

Elective cardiac surgery patients were matched with individual patients from the ITU group on the basis of the identified matching criteria. A nurse from the cardiac group

was given a list of these matching criteria and selected patients from the cardiac group who met these criteria. These patients were then approached by the cardiac liaison nurse who introduced them to the study, and asked them if they and their closest relative would be interested in participating. Patients were asked permission for the researcher to contact them with further information about the study. Once this permission was given, the researcher was given a list of patients and their closest relative who met the matching criteria and were willing to be approached. These patients and closest relative were then sent information sheets (appendix 7 & 8), consent forms (appendix 3a & b) and stamped addressed envelopes in the post. A contact number was also made available through which participants could contact the researcher. Once consent forms were returned the researcher contacted the patients by phone and a research appointment was arranged.

Twenty-five elective cardiac surgery patients were asked to participate in the research. Ten declined to take part in the study, leaving 15 participants. This was a 60% response rate. Reasons for declining were not available; non-completion or non-return of the consent forms were taken as non-consent and due to ethical reasons this was not pursued. It was not possible to find matched elective cardiac surgery patients for five of the ITU group. These five ITU patients had families with small children or adolescents. This was a difficult family life cycle stage to match as the majority of elective cardiac surgery patients are in the later stages of life. In total, 15 elective cardiac surgery patients and their closest relative participated in the research.

MEASURES

Demographic Information:

Consent to examine medical notes was gained in the consent forms (Appendix 3a & b). The demographic information that was obtained from the medical notes is as follows.

ITU patients receive a measure of illness severity during their first 24 hours in ITU. This is called the Acute Physiology and Chronic Health Evaluation (APACHE) II score (Knaus, 1985). It computes a severity of illness score for ITU patients and allows a predicted death rate to be calculated. The higher the Apache-II score, the greater the chance of death. A score of 24 for example equates to a 49.7% chance of death. This information was collected so that potential readers of the study could compare this sample with other ITU populations.

The patients length of stay on ITU (in days), their presenting illness, previous illness history (acute/chronic), age and gender were also obtained. Relatives were asked their age during the time taken to complete the questionnaires.

Elective cardiac surgery patients do not receive a measure of illness severity, so this information is not available for comparison. However their length of hospital stay (in days), the type of surgery they had, age and gender was documented. Previous illness history was already determined in this group as this was the matching criteria which formed the basis of their recruitment in to the study. Relatives were asked their age during the time taken to complete the questionnaires.

Additional demographic information was gained from the ITU and cardiac relatives during questionnaire completion. Relatives were asked the last occupation of their relative as well as their own. This information was obtained so that patients' socio-economic status could be calculated based on their occupation. Socio-economic status was calculated using the Registrar Generals' 'Standard Occupational Classification (SOC2000)'. A summary of the structure of this classification system can be viewed in Appendix 9.

Relatives in the ITU group also completed a genogram with the researcher. This was used to calculate the stage of the family life cycle which was used to match participants across the groups. Participants were matched according to the stages put forward by Carter and McGoldrik (1980). They postulate that families pass through a series of stages in their development. Each stage brings new tasks, which the family must negotiate. Figure 5 below describes the stages and tasks which were used to match the two groups in the present study.

FIGURE 5: Carter and McGoldrick's (1980) Six Stages of the Family Life Cycle

STAGE	MAJOR TASK
1. Unattached young adult who is between families	Successful separation of parent and young adult
2. New marriage	Commitment to a new family system
3. Family with young children	Accepting new members in to the system
4. Family with adolescents	Allowing increasing independence of the children within the family's boundaries
5. Launching children and moving on	Accepting many exits and entrances in to the family
6. Later life	Accepting shifting generational roles and death

Difficulties achieving these tasks, or difficulty negotiating the move from one life cycle stage to another is argued to result in the presentation of problems for the family (Barnhill and Longo, 1978). Family research commonly reports differences in findings across the differing stages of the family life cycle (Epstein et al., 1993).

As with previous illness history, family life cycle was already determined for the elective cardiac surgery patients as it formed the basis of recruitment in to the study.

STUDY VARIABLE MEASURES

Psychological Adjustment

Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)

(Appendix 10)

This is a self-report measure designed for use with medical patients as a screening tool for anxiety and depression. It allows clinicians to gauge the severity of anxiety and depression being reported. The HADS avoids the pitfalls of other measures by using items that will not be contaminated by medical patients' physical symptomatology. This measure has also been used frequently with the ITU population and is considered a valid tool for assessing ITU related psychological problems (Eddleston et al., 2000; Jones et al., 2001b).

The HADS is made up of a total of 14 items. These produce two sub-scales of anxiety (seven items) and depression (seven items).

The scale is comprised of 14 statements related to anxious and depressed feelings. For each statement respondents must chose which of four options best describes how they have been feeling in the past week. For example:

I feel tense or 'wound up'

Most of the time

A lot of the time

From time to time, occasionally

Not at all

Each item is scored from 0-3. Maximum total scores are 21 on both scales.

Normative Data

Interpretation of the HADS is based on the use of cut-off scores. These scores have been derived from two main studies using 100 medical out-patients (Zigmond and Snaith, 1983) and 573 cancer patients (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). On the basis of these two studies, Zigmond and Snaith recommend the cut-off of 8 or more be used to indicate possible clinical disorder and 11 or more be used to indicate probable clinical disorder. Comparative data is also available for female cardiac patients (Roberts, Bonnici, Mackinnon & Worcester, 2001). A recent study by Crawford, Henry, Crombie & Taylor (2001) provides normative data for the HADS based on the responses of 1792 members of the general public. Percentile tables are available in this study to allow meaningful interpretation. Data available from this study have caused the authors to raise questions about the validity of the cut-off scores (Crawford et al., 2001). The authors suggest that the higher cut-off score of 10-11 is more valid and produced a percentage in their normative sample that closely approximated figures for anxiety and depression produced by epidemiological studies such as Horwath and Weissman (1995).

Reliability

Internal Consistency

Internal consistency has been shown to be high with Cronbach's alpha of 0.93 for anxiety and 0.90 for depression (Moorey et al., 1991).

Concurrent Validity

A study correlating HADS scores with 5-point psychiatric rating scales for anxiety and depression produced significant correlations of $r = 0.54$ for anxiety and $r = 0.79$ for depression (Zigmond and Snaith, 1983)

Construct Validity

Moorey et al. 1991 study with 583 cancer patients found two emerging factors (i.e. anxiety and depression) as the result of a factor analysis computation. These two factors accounted for 53% of the variance. This study yielded correlations between the two factors of anxiety and depression of 0.37 for men and 0.55 for women. The more recent 'normative sample' study by Crawford et al (2001) found a correlation of $r = 0.53$ between anxiety and depression for the general population. This is highly significant ($p < 0.001$). This along with other studies (Herrmann, 1997) suggests that Zigmond and Snaith's claims that the anxiety and depression measures are independent of one another may be unfounded (Crawford et al., 2001). Crawford et al. (2001) suggest that combining the anxiety and depression scores to provide a total score of psychological distress could be achieved with the HADS.

A qualitative question was designed to provide examples of relatives' actual ITU / elective cardiac surgery experiences and to gain further information about their adjustment. It was hoped that the findings would provide supplementary information to the HADS scores and the analysis concerning group differences.

Qualitative Question:

' What comes to mind when you think of life before ITU and now?'

Family Functioning

McMaster Family Assessment Device (FAD) (Epstein, Baldwin and Bishop, 1983)

(Appendix 11)

This is a 60 item self-report screening instrument constructed from the McMaster model of family functioning (Epstein et al., 1978). It assesses family functioning in the following domains:

Problem solving (6 items)

Communication (9 items)

Roles (11 items)

Affective responsiveness (6 items)

Affective involvement (7 items)

Behaviour control (9 items)

General functioning (12 items). This scale is thought to be reflective of the families overall functioning and will be the measure used in the present research to represent family functioning (Epstein et al., 1983). The other domains may be used for post-hoc, exploratory analysis.

It is a self-report scale to be completed by members of the family. The measure consists of 60 statements about families. Respondents must consider each statement and decide how much they agree the statement reflects their own family and its current functioning. Respondents can chose from the following responses:

Strongly agree

Agree

Disagree

Strongly disagree

In this study 'family' was considered to be those members of the current family unit i.e. those family members currently living at home.

It is estimated that time for completion of this measure is 15-20 minutes.

Scores are calculated for each dimension of the scale and range from 0-4. Cut-off scores are available for the measure (Miller et al., 1985) which allow scores to be categorised as either representative of healthy or unhealthy functioning. The higher the score the more unhealthy the functioning. Family scores are calculated by calculating the families mean score as suggested by Miller, Epstein, Bishop & Keitner (1985).

Original development of the FAD was based on data derived from the responses of 503 individuals. These made up the original standardisation sample and comprise of a mixture of clinical (N=218) and non-clinical (N=98) families. This data resulted in the original 53-item measure (Epstein et al., 1983). Means and standard deviations of the normative group are available (Epstein et.al., 1983). Subsequent revisions of the FAD have resulted in the addition of another 7 items to the scale resulting in the 60-item measure. Greater reliability was achieved through addition of the 7 items in the 60-item version.

Normative data (means and standard deviations) for this revised version are also available (Kabacoff, Miller, Bishop, Epstein & Keitner 1990) and are based on data collected from non-clinical (N=627), Psychiatric (N=1,138) and medical (N=298) families.

This study utilised the 60-item version and reliability and validity information will be drawn where possible from studies using the 60-item measure.

Reliability

Internal Consistency

Internal consistency calculations are available across the normative samples for the 60-item version. Alpha scores for each domain are stated below (Kabacoff et al., (1990):

Problem solving = 0.74 – 0.80

Communication = 0.70 – 0.76

Roles = 0.57 – 0.69

Affective responsiveness = 0.73 – 0.75

Affective Involvement = 0.76 – 0.78

Behaviour Control = 0.70 – 0.73

General Functioning = 0.83 – 0.86

Kabacoff et al., (1990) concluded that with the exception of the roles scale, all scales meet Nunallys' (1978) standard criteria for reliability of a research tool. They advise that the roles scale is therefore interpreted with caution.

Test-Retest Reliability

Test-retest studies have been completed with the 53-item version of the scale on a sample of 45 non-clinical participants (Miller et al., 1985). These have utilised 1 week repeat scores and produced the test-retest estimates: Problem solving (0.66), Communication (0.72), Roles (0.75), Affective Responsiveness (0.76), Affective

Involvement (0.67), Behaviour Control (0.73), and General Functioning (0.71). These correlation's demonstrate that the FAD is reliable over short periods of time.

Validity

Concurrent Validity

Concurrent validity was assessed by administering the FAD alongside the Family Unit Inventory (FUI) and the FACES II (based on the circumplex model of family functioning (Olson, Sprenkle and Russell, 1979). Correlation's between the FAD and FUI matched closely with theoretical predictions and provide evidence for the scales concurrent validity (Miller et al., 1985). However correlation's between the FAD and FACES II were not in agreement with theoretical predictions. However the authors discuss that similar relationships between the FACES II and the FUI have also been discovered and that this may be a reflection of a differing theoretical basis to the measures (Miller et al., 1985). The FACES – II scale measures adaptability and cohesion. Each scale ranges from one extreme to another (e.g. rigid to chaotic) and the model implies that both extremes are pathological. The model therefore assumes a curvilinear relationship. This is different to the FAD and FUI which impose a linear relationship with higher scores representing greater pathology. Analysis for concurrent validity however showed that this curvilinear relationship was not present between FAD and FACES-II scores and FUI and FACES-II scores and instead a linear relationship existed. They conclude that FACES-II may share a linear relationship with health.

Discriminative Validity

FAD scores (53 item version) were compared with an experienced clinicians ratings' of the same families' functioning (Miller et al., 1985). Those families rated as unhealthy by the clinician displayed significantly higher scores on 6 of the 7 FAD dimensions than families rated by the clinician as unhealthy. The behaviour control dimension did not reach significance ($p = 0.12$) and therefore did not display adequate discriminative validity. With the exception of the behaviour control dimension, this lends support to this measures ability to discriminate healthy from unhealthy families. The behaviour control domain may not have reached significance due to the small numbers used in the study ($N = 42$).

Construct Validity

Confirmatory factor analysis of the FAD revealed that the FAD has 'highly similar factor structure in non-clinical, psychiatric and medical samples' (Kabacoff et al., 1990). These studies have also shown that 'over 90% of FAD items loaded on factors hypothesised by the McMaster model'. (Kabacoff et al., 1990). Kabacoff et al. (1990) conclude that 'the structure of the FAD appears to correspond well to the hypothesised theoretical structure from the McMaster Model'.

The measure is also reported to be unrelated to measures of social desirability, (Epstein et al., 1983).

Other measures used were:

- **The Severity of Illness Continuum (appendix 12).**

Previous literature has discussed how there can often be frustrations between patient and relative due to patients having no memory of how ill they were in intensive care and often having unrealistic expectations about recovery (Griffiths et al., 1996; Speedling, 1980). This measure aimed to examine if there was indeed a discrepancy between patients' and relatives' recall of how ill they were and if this discrepancy had any relationship to psychological adjustment in patient and relative.

Both patients and relatives were asked to place a cross on the 21.7cm long continuum to mark how ill they remember themselves or their relative being while they were in intensive care / cardiac unit. The discrepancy was calculated by subtracting the length of the patients and relatives indicators on the continuum. This difference score was then recorded as their discrepancy.

PROCEDURE

A research timeline is contained within Appendix 13 and outlines the earlier stages of the research process. The research gained ethical permission from Central Manchester Local Research Ethics Committee in October, 2001. A copy of this ethical approval is shown in appendix 14. Ethical issues for the study concerned the referral paths which would be used when psychological problems were detected. Already existing referral pathways from the ITU follow-up group were adopted for relatives. These were that mild or moderate psychological difficulties would be reported to patients' GP's and that those patients presenting with severe psychological problems can be referred to the Psychiatrist who is attached to the ITU follow up team. GP's are routinely informed of patients' attendance at the follow up appointment and of their progress. GP's were also informed of the patients and the relatives participation in the research and of any problems identified. Informing GP's was a requirement of the ethics board.

Recruitment for the study began in early December, 2001 and ended in April, 2002. Details of recruitment procedures are outlined earlier in the methods section. Data collection began in early December 2001 and ended in May 2002.

ITU Patients and their Closest Relatives

Patients and their closest relative attended the follow-up appointment together. Initially, they met together with the researcher and follow-up nurse, who set the agenda for the appointment, clarified any questions and reaffirmed consent. Patients remained with the ITU follow-up nurse and relatives were interviewed separately in an adjacent room by the researcher.

Patients:

The follow-up nurse administered the research questions first and then progressed on to the routine follow-up questions, which were part of the already established clinic. Research questions were read aloud to the patients and completed collaboratively. This method was chosen so that any questions that caused confusion could be clarified without causing false responses

Research measures completed by the patient were:

1. HADS
2. The FAD
3. The severity of illness continuum

Closest Relative:

Relatives completed the following questionnaires with the researcher:

1. HADS
2. FAD
3. The severity of illness continuum
4. Genogram
5. Qualitative question

All questionnaires were read aloud to the participants and completed with the researcher collaboratively. This method was chosen so that any questions that caused confusion could be clarified without causing false responses.

If HADS scores were elevated a discussion about the source of worries took place. This questioning took place to enable the researcher and relative to think about appropriate referral pathways. If scores were elevated to a clinical level the researcher gained consent to inform their GP's of these scores and ascertained if they would like any help with these current problems. GP's were informed of these discussions. Informing GP's of psychological difficulties was routine clinic practice for patients but not for relatives as they are not routinely assessed.

When completing the FAD respondents were asked to reply as they considered their family (those people currently living in the family home) to be functioning at present. Once the relative and researcher had completed measures (approximately 45 minutes) the relative re-joined the patient and follow-up nurse. This allowed relatives time to ask the nurse any questions about ITU or the patients recovery that they may have been concerned about.

Comparison Group – Elective Cardiac Surgery Group

Participants were invited to attend for a research appointment 3 months after they had been discharged from the CSU. Unlike the ITU group this appointment time was not combined with a routine follow up appointment and patients did not see a nurse. The researcher interviewed both the patient and relative separately. It was anticipated that this appointment would be of a slightly longer duration of one and a half hours as both needed to be interviewed separately. However appointments typically lasted an hour with this group also. Patients and relatives were administered the same research related questionnaires in the same order as the ITU group and using the same procedure. The severity of illness continuum was not administered to this group as

this question was specifically designed to address if ITU patients and relatives differed in their perception of how ill they remember themselves or their relative being while they were in ITU. There was not a comparable time point with the comparison group when this question could be asked. The qualitative question was reworded so that it read ‘What comes to mind when you think of life before cardiac surgery and after?’

Figure 4 summarises the research design and the measures used.

ANALYSIS

SPSS for windows, version 10 was used to analyse the data and test the hypotheses.

All of the main variables were analysed to check that they were normally distributed using the Kolmogorov-Smirnov Z test. This was to ascertain if the data needed to be analysed using parametric or non-parametric statistics.

Differences between the ITU and elective cardiac surgery group were calculated using Independent samples t-tests. The cut-off scores for clinical levels of anxiety/depression and healthy/unhealthy families were not utilised for the analysis. Instead the whole range of scores were used. Therefore any differences found between groups would tell us that one group is scoring higher on the measures, not that they are clinically depressed or that their families are unhealthy.

The open question was analysed with a thematic analysis which utilised the principles of Interpretative Phenomenological Analysis (IPA) (Smith, Jarman and Osborn, 1999).

Partial correlation's were utilised to test hypotheses concerned with relationships between the main study variables.

Post-hoc analysis occurred to examine how the difference in patients' and relatives' perception of family functioning was related to psychological adjustment. A paired samples t-test was utilised to test if patients' and relatives' perceptions of family functioning were significantly different. The relationship between discrepant perceptions of family functioning and psychological adjustment was calculated by

computing a difference score (patients' family functioning score – relatives' family functioning score). This difference was then correlated with the adjustment scores to see if any relationship existed using partial correlation's.

Additional analysis of the relationship between psychological adjustment and family functioning occurred considering the relationship between the other domains (problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control) of the FAD and psychological adjustment.

The research model proposed in the introduction section was analysed using a linear regression model to ascertain if any of the models factors could explain a significant amount of the variance in the study variables.

A paired sample t-test analysis was used to test the hypothesis specific to the ITU population.

RESULTS

Outline of Results:

The two groups (ITU/Elective cardiac surgery) are first described in relation to their demographic features. The results then move on to consider the research hypotheses posed at the beginning of the thesis. Differences between the two groups are calculated. All hypotheses and analyses are considered for patients and relatives within each group. The supplementary information provided by the qualitative analysis of the open question is presented along with consideration of differences in themes between the two groups. The results then go on to consider the relationship of family factors to psychological adjustment. This is followed by a post-hoc analysis of the role of family functioning discrepancy scores and the relationship of the FAD domains to psychological adjustment. These analyses are then summarised by testing of the research model using linear regression. The results are then concluded by addressing the specific ITU questions, namely the relationship of a discrepancy in 'illness severity' perception to psychological adjustment.

Participant Demographics

Twenty ITU patients and their closest relative participated in the research. In the elective cardiac surgery group a total of 15 patients and their closest relative were matched to the ITU group. The demographic details of these two groups are outlined in the tables below. As is evident from Table 2, the majority of patients are male and relatives female. The two groups are of similar ages, with no significant differences being found between the groups on age.

Table 2: Descriptive Data For Gender And Age In The ITU and Elective Cardiac

Surgery Group

	GROUP			
	ITU GROUP		ELECTIVE CARDIAC SURGERY GROUP	
	PATIENTS	RELATIVES	PATIENTS	RELATIVE S
<u>GENDER</u> Male: Female	15 : 5	5 : 15	12 : 3	3 : 12
<u>AGE</u> Mean	54.15	53.3	60.07	60
SD	16.85	13.94	11.60	12.51
Minimum	20	25	41	43
Maximum	80	75	76	78
Range	60	50	35	35

Table 3 provides a breakdown of socio-economic classes for ITU and elective cardiac surgery patients and relatives. This was calculated from the patients' and relatives' present or last occupation. As is evident from this table, the spread of socio-economic groups is relatively even and no significant differences in class were demonstrated between the ITU and elective cardiac surgery groups.

Table 3: Breakdown Of Socio-Economic Classes Within The ITU and Elective Cardiac Surgery Groups

SOCIO-ECONOMIC CLASSIFICATIONS	Number Of ITU Group From Each Socio-economic Class		Number Of Elective Cardiac Surgery Group From Each Socio-economic Class	
	Patients	Relatives	Patients	Relatives
Managers and Senior Officials	2	0	2	2
Professional Occupations	2	0	3	0
Associate Professional and Technical Occupations	2	1	0	1
Administrative and Secretarial Occupations	2	2	3	3
Skilled Trades Occupations	2	2	2	0
Personal Service Occupations	1	7	0	1
Sales and Customer Service Occupations	2	2	0	4
Process, Plant and Machine Operatives	2	1	3	0
Elementary Occupations	5	4	2	4

The majority of participants were in the later stages of the family life cycle. This is clearly evident in Table 4

Table 4: Frequency Of Family Life-Cycle Stage For ITU And Elective Cardiac Surgery Group

	Number Of ITU Group From Each Stage Of The Family Life Cycle	Number Of Elective Cardiac Surgery Group From Each Stage Of The Family Life Cycle
Unattached young adult who is between families	0	0
New marriage	0	0
Family with young children	2	0
Family with adolescents	3	2
Launching children and moving on	4	3
Later life	11	10

ILLNESS VARIABLES

Table 5 below illustrates the breakdown of presenting illnesses for the ITU group. It reveals that the ITU group presented with a variety of illnesses on admission to ITU. Their presenting illness is somewhat different to their illness history which is presented in Table 7 below.

Table 5: Presenting Illnesses Of The ITU Group

PRESENTING ILLNESS	FREQUENCY
Asthma	2
Bilateral pneumothorax	1
Cardiac arrest	1
Cholecystectomy leak	1
Chronic obstructive airways disease	1
Epileptic fit	1
Sepsis	3
Perforated duodenal ulcer	1
Perforate sigmoid	1
Pneumonia	1
Respiratory failure	2
Complications of surgery	4
Ulcerative colitis	1

The elective cardiac surgery group are a mix of patients who have had heart by-pass surgery and valve replacement surgery (Table 6). The majority of patients have had triple and quadruple by-pass surgery.

Table 6: Frequency Of Surgery Type For Elective Cardiac Surgery Group

TYPE OF SURGERY	FREQUENCY
Double by-pass	2
Triple by-pass	6
Quadruple by-pass	5
Quintuplet by-pass	1
Valve replacement	1

Patients' previous illness history was also recorded and is presented in Table 7. As is evident from Table 7, there is a fairly equal number of patients with acute and chronic illness histories. The mean APACHE-II score for ITU patients is 14.65. This equates to a 20.1% predicted death rate. Comparison of length of stay is not possible as for the ITU group, length of stay refers to ITU stay, and for cardiac patients this refers to total stay in hospital.

Table 7: Descriptive Data For Illness Variables Of ITU And Elective Cardiac

Surgery Patients

	GROUP	
	ITU GROUP	ELECTIVE CARDIAC SURGERY GROUP
<u>Illness history</u> Acute: Chronic	10:10	7:8
<u>Apache-II Scores</u> Mean Minimum Maximum Range Standard deviation	14.65 8 24 16 4.51	
<u>Length of ITU stay/ Hospital stay (days)</u> Mean SD Minimum Maximum Range	19.05 17.49 2 57 55	7.13 2.42 3 12 9

The percentage of patients and relatives scoring within the borderline or clinical range for anxiety and depression are reported below in Table 8. These figures were calculated to allow for comparisons with other populations and to compare with the previous ITU literature.

Table 8: Prevalence Rates (Frequency and Percentages) Of Anxiety And Depression In Patients And Relatives (HADS Score >10) In The ITU And Elective Cardiac Surgery Group

	GROUP			
	ITU GROUP		ELECTIVE CARDIAC SURGERY GROUP	
	PATIENTS	RELATIVES	PATIENTS	RELATIVES
ANXIETY	1(15%)	7(35%)	1(6.66%)	4(26.66%)
DEPRESSION	1(5%)	3(15%)	0(0%)	0(0%)

An Independent samples t-test was calculated between relatives' and patients' anxiety and depression scores within the two groups. No significant differences between patients' and relatives' scores exist within the elective cardiac surgery group. Within the ITU group there is no significant difference between patients' and relatives' depression scores. However, ITU patients and relatives do differ significantly in their levels of anxiety, with relatives reporting significantly higher levels of anxiety than patients. Result of the t-test are reported below in Table 9:

Table 9: T-Test Analysis Of Difference Between Patients And Relatives Anxiety

Scores In The ITU Group

	MEAN	SD	T	DF	SIGNIFICANCE (2-TAILED)
PATIENTS' ANXIETY SCORES	4.55	2.86	-2.65	38	0.01
RELATIVES' ANXIETY SCORES	8.45	5.86			

STATISTICAL ANALYSIS

A Kolmogorov-Smirnov test was performed on all of the main study variables. The following significance scores were obtained:

0.23 for anxiety (as measured by the HADS)

0.11 for depression (as measured by the HADS)

0.53 for the general functioning score on the FAD

All are above 0.05 and are therefore normally distributed. Parametric statistics were therefore used to test the research hypotheses.

As is evident from the descriptive data, the sample suffers from some gender biases, in that the majority of patients are male and the majority of relatives are female. It may be then that any differences or relationships found between patients and relatives and the main study variables may be the result of gender differences rather than their role as patient or relative. This and the fact that there are known gender differences in mental health statistics (Ussher, 1997) suggests that gender should be partialled out in the analyses.

RESEARCH QUESTIONS AND HYPOTHESES TESTING:

The four main research questions and their relating hypotheses were tested by analysis of group differences and consideration of relationships between the main study variables.

Research Question 1: Are ITU patients and their relatives a unique sample of medical patients?

GROUP DIFFERENCES:

Group differences were calculated using Independent samples t-test analysis, as parametric assumptions had been satisfied. Each hypothesis was tested for patients and relatives separately.

Hypothesis A:

There will be no significant difference between the ITU group (patients and relatives) and the elective cardiac surgery group (patients and relatives) on measures of psychological adjustment (as measured by anxiety and depression scores of the HADS).

As is evident from Tables 10 and 11, mean scores for anxiety and depression in both groups are below the recommended cut-off (>10) for clinical significance (Crawford et al., 2001). This suggests that the typical ITU and elective cardiac surgery patient in this study are not clinically anxious or depressed.

Patients:

As is evident from Table 10, no significant differences were found between patients in the ITU and cardiac group. For patients then, hypothesis A was accepted.

Table 10: Independent Samples T-Test Results For Differences Between ITU And Elective Cardiac Surgery Patients On The Measures Of Psychological Adjustment.

	MEAN	SD	T	DF	SIGNIFICANCE (2-TAILED)
ANXIETY					
ITU patients	4.55	2.86	-1.59	33	0.12
Cardiac patients	6.20	3.23			
DEPRESSION					
ITU patients	3.90	2.95	-0.32	33	0.97
Cardiac patients	3.93	3.08			

Relatives:

As is evident from Table 11, ITU and elective cardiac surgery relatives do not differ in their levels of anxiety. However, the two groups do differ in their levels of depression. ITU relatives are significantly more depressed than cardiac surgery relatives. For relatives then, hypothesis A is rejected as differences between the groups existed.

Table 11: Independent samples T-test results for differences between ITU and Elective Cardiac Surgery relatives on the measures of psychological adjustment.

	MEAN	SD	T	DF	SIGNIFICANCE (2-TAILED)
ANXIETY					
ITU relatives	8.45	5.86	0.86	33	0.39
Cardiac relatives	6.80	5.29			
DEPRESSION					
ITU relatives	5.40	5.07	2.12	33	0.04*
Cardiac relatives	2.40	2.35			

* Difference is significant at the 0.05 level

Hypothesis B:

There will be no significant difference between the ITU group (patients and relatives) and elective cardiac surgery group (patients and relatives) on perceived family functioning.

As is evident from Table 12, the mean general family functioning scores for patients and relatives in both the ITU and elective cardiac surgery group fall below 2.0. This is the cut-off score recommended by Miller et al. (1985) to establish healthy from non healthy family functioning. This suggests that the typical ITU and elective cardiac surgery families in this study have family functioning which would be classified as healthy.

As shown in Table 12, ITU patients and cardiac patients do not differ in their perceptions of family functioning. For patients then, hypothesis B is accepted. However ITU and cardiac relatives do differ in how they perceive their family functioning with ITU relatives perceiving their family functioning as significantly more unhealthy than cardiac relatives. For relatives, hypothesis B is rejected.

**Table 12: Independent Sample T-Test Results Examining The Difference
Between ITU And Elective Cardiac Patients On Perceived Family Functioning**

	MEAN	SD	T	DF	SIGNIFICANCE (2-TAILED)
Patients' perceived family functioning (General functioning score)					
ITU patients	1.85	0.43	1.45	33	0.16
Cardiac patients	1.63	0.47			
Relatives' perceived family functioning (General functioning score)					
ITU relatives	1.98	0.44	2.81	33	0.008**
Cardiac relatives	1.60	0.33			

**** Difference is significant at the 0.01 level**

OPEN QUESTION ANALYSIS

Open question:

“What comes to mind when you think of life before ITU/Cardiac surgery and now?”

The open question was designed to provide supplementary information to the quantitative analyses of difference between the two groups and to provide a richer reflection of the two groups experiences with illness.

The open question was analysed using thematic analysis based on the principles of Interpretative Phenomenological Analysis (IPA). Themes which emerged in the ITU and elective cardiac surgery are reported below in Table 13.

As is evident from the table the ITU responses provided ‘richer’ ‘data’ than the cardiac group. The over-riding impression from the cardiac group was the sense of relief and the chance for new beginning which the operation brought. Although there was recognition that the recovery period was stressful, as with the ITU group, the improvements which the operation brought tended to over-ride these worries. This was not the case with the ITU group who were more troubled by the difficulties which the recovery period brought to them. The sense from the open question with the ITU group was often that the experience had been life altering and that the impact was much more profound.

Table 13: Main Themes Produced From Thematic Analysis

<p style="text-align: center;">ITU THEMES Illustration of Themes' Content</p>	<p style="text-align: center;">ELECTIVE CARDIAC GROUP THEMES Illustration of Themes' Content</p>
<p><u>THEMES RELATED TO THE RECOVERY PERIOD</u></p> <p>Hypervigilance For Illness Symptoms:</p> <ul style="list-style-type: none"> ➤ “If any little thing went wrong I would worry” ➤ “When he first came home, I would keep myself awake to check he was still breathing” ➤ “If I am not with him, I worry that the same thing will happen again” <p>Carer Role:</p> <ul style="list-style-type: none"> ➤ “Sense of responsibility” <p>Social Isolation:</p> <ul style="list-style-type: none"> ➤ “Now we are in all the time” ➤ “Not able to go out as much as before” <p>Relationship Strains:</p> <ul style="list-style-type: none"> ➤ “freedom in relationship has lessened” ➤ “more irritable with each other” <p>Role Changes:</p> <ul style="list-style-type: none"> ➤ “doing a lot more jobs now” <p>Practical Difficulties Returning Home:</p> <ul style="list-style-type: none"> ➤ “We were not aware of the difficulties we would have practically when he came home” ➤ “Did not have any back up at home” 	<p><u>THEMES RELATED TO THE RECOVERY PERIOD</u></p> <p>Hypervigilance For Illness Symptoms:</p> <ul style="list-style-type: none"> ➤ “I was worried every time that she moved” <p>Social Isolation:</p> <ul style="list-style-type: none"> ➤ “Holidays have been put on a hold” <p>Relationship Strains:</p> <ul style="list-style-type: none"> ➤ “irritable” <p>Role Changes:</p> <ul style="list-style-type: none"> ➤ “He was always the fit and strong one before” ➤ “Had to take on a lot of the jobs”
<p><u>GRADUAL REDUCTION OF PROBLEMS:</u></p> <ul style="list-style-type: none"> ➤ “normal way of life gradually coming back” ➤ “Now things are settling back down” 	
<p><u>COGNITIVE APPRAISALS:</u></p> <p>Increased Realisation of Mortality</p> <ul style="list-style-type: none"> ➤ “makes you think that life can be short” <p>Life Altering:</p> <ul style="list-style-type: none"> ➤ “Normal way of life has gone” ➤ “Outlook on life changed” 	<p><u>COGNITIVE APPRAISALS:</u></p> <p>Increased Realisation of Mortality:</p> <ul style="list-style-type: none"> ➤ “What if he were to die – what would it be like without him?”
<p><u>CHANGES IN THE PATIENT:</u></p> <ul style="list-style-type: none"> ➤ “Became more anxious” ➤ “He is more sensitive now” 	

Table 13 Continued

ITU THEMES	ELECTIVE CARDIAC SURGERY THEMES
<p><u>PATIENT COGNITIVE DIFFICULTIES</u></p> <ul style="list-style-type: none"> ➤ “memory problems” ➤ “Confused, disorientated” 	<p><u>PSYCHOLOGICAL IMPACT OF HAVING OPERATION CANCELLED:</u></p> <ul style="list-style-type: none"> ➤ “We got all geed up and then it was cancelled – she got quite depressed after that”
<p><u>POSITIVE CONSEQUENCES</u></p> <ul style="list-style-type: none"> ➤ “We show each other much more tenderness and respect” ➤ “It was a life turning point - life is much more positive now” 	<p><u>POSITIVE CONSEQUENCES</u></p> <ul style="list-style-type: none"> ➤ “Now things just don’t seem so important” <p><u>POSITIVE INTERPRETATIONS:</u></p> <p>Relief – Improvement:</p> <ul style="list-style-type: none"> ➤ “We are looking forward to things now” ➤ “Now that he has survived we know that he will have a better quality of life”

Research Question 2: What influence do family factors (family functioning and relatives adjustment) have on psychological adjustment of patient and relative?

RELATIONSHIPS BETWEEN VARIABLES

Family functioning was measured using the general functioning (GF) scale of the FAD which is thought to provide an overall measure of the family's functioning. One-tailed partial correlation's were calculated to see if there was any relationship between family functioning (GF score) and adjustment (anxiety and depression) while partialling out for the effects of gender. The relationship between patients' and relatives' psychological adjustment was computed using a two-tailed correlation and is marked in the table to establish this difference. A table of the correlation's are shown below for patients and relatives of both the ITU and cardiac group.

ITU GROUP

Hypothesis C

There will be a significant positive relationship between family functioning scores and psychological adjustment (as measured by anxiety and depression on the HADS) in patients and relatives.

As can be seen from Table 14, significant correlation's were found between relatives' perceived family functioning and anxiety ($p < 0.05$) and also between relatives' perceived family functioning and depression scores ($p < 0.01$). The correlation found was positive, as was predicted. Therefore, as the perception of family functioning becomes more unhealthy so does the relatives' levels of anxiety and depression. For ITU relatives then, hypothesis C is accepted. This was not the case for ITU patients

where there were no significant differences found between perceived family functioning and psychological adjustment and hypothesis C was rejected.

Hypothesis D

There will be a significant relationship between patients' and relatives' psychological adjustment (as measured by anxiety and depression on the HADS).

Calculated correlation's between patients' and relatives' psychological adjustment are displayed in Table 14. No significant relationships were found between ITU patients' and relatives' anxiety scores or between ITU patients' and relatives' depression scores. Hypothesis D is therefore rejected for the ITU group.

ITU Group

Table 14: Partial Correlation Coefficients for The ITU Group

Variables	1 (FF-R)	2 (FF-P)	3 (A-R)	4 (A-P)	5 (D-R)	6 (D-P)
1. Family Functioning (relative)	1.00		0.42*		0.58**	
2. Family functioning (patient)		1.00		0.25		0.14
3. Anxiety (relative)	0.42*		1.00	0.18 (2-tailed)		
4. Anxiety (patient)		0.25	0.18 (2-tailed)	1.00		
5. Depression (relative)	0.58**				1.00	0.22 (2-tailed)
6. Depression (patient)		0.14			0.22 (2-tailed)	1.00

* Correlation is significant at the 0.05 level (1-tailed)

** Correlation is significant at the 0.01 level (1-tailed)

ELECTIVE CARDIAC SURGERY GROUP

Hypothesis C

There will be a positive relationship between family functioning scores and psychological adjustment (as measured by anxiety and depression on the HADS) in patients and relatives

As can be seen in Table 15, significant relationships were found between relatives' perceived family functioning and anxiety ($p < 0.05$) as well as between relatives' perceived family functioning and depression ($p < 0.01$). As predicted these correlation's were in a positive direction. Therefore, as the perception of family functioning becomes more unhealthy so do the relatives' levels of anxiety and depression increase. Therefore for elective cardiac surgery relatives hypothesis C was accepted. However, no significant relationships were found between patients' perceptions of family functioning and psychological adjustment and therefore for elective cardiac surgery patients hypothesis C was rejected.

Hypothesis D

There will be a significant relationship between patients' and relatives' psychological adjustment.

As with the ITU group, no significant relationships were found between patients' and relatives' anxiety scores or between patients' and relatives' depression scores.

Therefore hypothesis D was rejected for the elective cardiac surgery group.

Table 15: Partial Correlation Coefficients for the Elective Cardiac Surgery Group

Variables	1 (FF-R)	2 (FF-P)	3 (A-R)	4 (A-P)	5 (D-R)	6 (D-P)
1. Family Functioning (relative)	1.00		0.5*		0.66**	
2. Family functioning (patient)		1.00		0.12		0.35
1. Anxiety (relative)	0.5*		1.00	0.26 (2-tailed)		
2. Anxiety (patient)		0.12	0.26 (2-tailed)	1.00		
3. Depression (relative)	0.66**				1.00	0.46 (2-tailed)
4. Depression (patient)		0.35			0.46 (2-tailed)	1.00

* Correlation is significant at the 0.05 level (1-tailed)

** Correlation is significant at the 0.001 level (1-tailed)

POST-HOC ANALYSIS

While collecting the data it became apparent that patients and relatives often differed in their perception of family functioning. A family functioning difference score was calculated by subtracting the relatives' family functioning score from the patients'. A negative value indicates that the relative perceives the family's functioning as more unhealthy than the patient.

Post-hoc analysis was computed to see if there was a significant difference between patients' and relatives' perceptions of family functioning and to see if discrepancies in perceived family functioning were related to psychological adjustment. Two extra hypotheses were generated and tested.

Hypothesis

There will be a significant difference in patients' and relatives' perception of family functioning.

This was tested using a paired samples t-test for both the ITU and elective cardiac surgery group. The results are displayed below in Table 16. Neither the ITU or elective cardiac surgery group produced significant differences in the patients' and relatives' perception of family functioning and therefore the hypothesis was rejected.

Table 16: Paired Samples T-Test Analysis Of The Difference Between Patients And Relatives Perceptions Of Family Functioning within the ITU and Elective Cardiac Surgery Groups

Paired differences					
Patients' family functioning score – relatives family functioning score	Mean	SD	T	Df	Significance (2-tailed)
ITU Group	-0.13	0.54	-1.08	19	0.29
Elective Cardiac Surgery Group	0.03	0.39	0.26	14	0.8

Hypothesis:

There will be a significant relationship between the difference score of perceived family functioning and psychological adjustment of patients and relatives

Partial correlation's (controlling for gender) were calculated to investigate if there was a relationship between discrepancy in family functioning (difference score) and psychological adjustment.

No significant differences between family functioning difference and anxiety and depression scores were found for ITU patients, elective cardiac surgery patients and elective cardiac surgery relatives. Therefore for ITU patients and the elective cardiac surgery group, this hypothesis was rejected. However, ITU relatives displayed significant relationships between family functioning difference scores and anxiety ($r=-0.49$, $p<0.05$, two tailed) and between family functioning difference score and depression ($r=-0.65$, $p<0.01$, two-tailed). Therefore, for ITU relatives, the hypothesis

was accepted. The nature of these relationships are illustrated below in Figures 6 and 7.

Both graphs illustrate the same relationship. As the family functioning difference score becomes increasingly negative (relatives perceive the family functioning as more unhealthy than patients) so do the relatives levels of anxiety (Figure 6) and depression (Figure 7) increase. As the patients perceive the family functioning as more unhealthy than the relatives (a positive difference score), so the relatives anxiety (Figure 6) and depression (Figure 7) decreases.

Figure 6: The Relationship between Family Functioning Difference Score and Anxiety

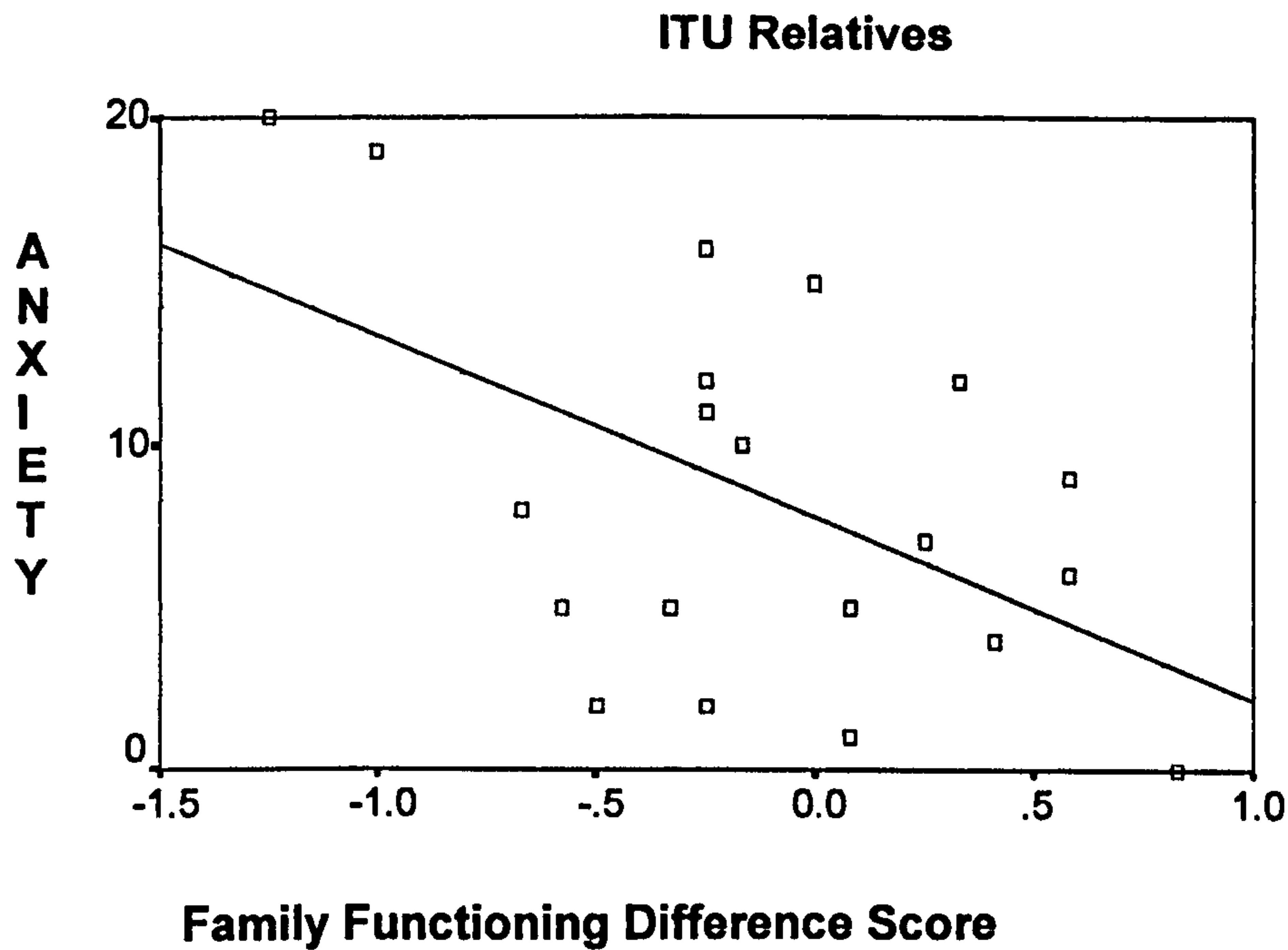
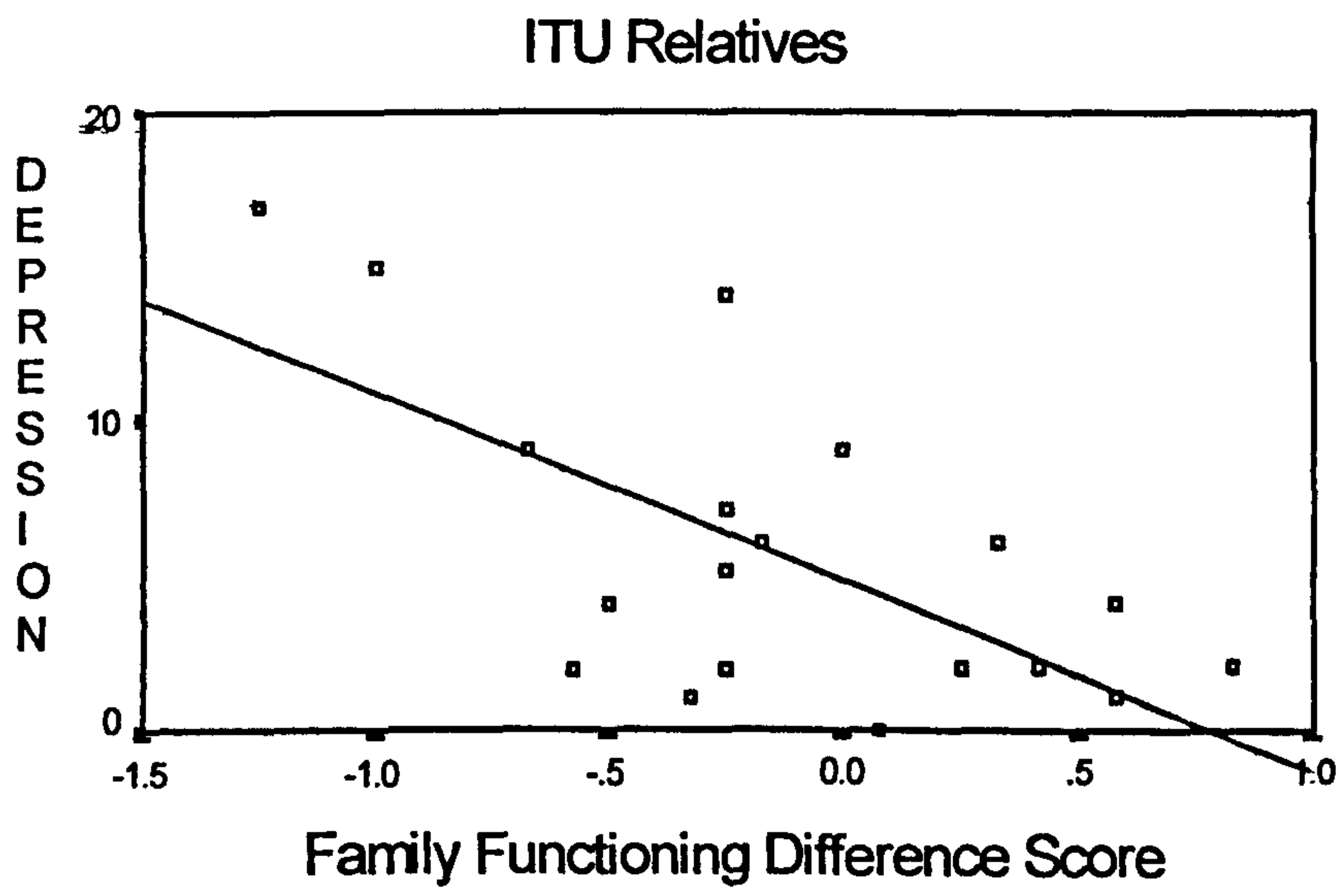


FIGURE 7: The Relationship Between Family Functioning Difference Score and Depression



Supplementary Analysis: The Relationship Between FAD Domains And Psychological Adjustment

The FAD domains of; problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control were correlated with anxiety and depression. This analysis was carried out to see if any particular aspects of family functioning were important for patients' and relatives' adjustment.

Again a one-tailed partial correlation was computed controlling for the effects of gender. Analyses are reported below. Those domains of the FAD that are significantly related to psychological adjustment tend to differ between the two groups and between patient and relative.

ITU Patients

The **problem solving** domain of the FAD was significantly correlated with **anxiety:**

$r = 0.49, p < 0.05$ (one-tailed)

The **behaviour control** domain of the FAD was significantly correlated with patients **depression scores:**

$r = 0.42, p < 0.05$ (one-tailed)

ITU Relatives

The **affective responsiveness** domain of the FAD was significantly correlated with **anxiety:**

$R = 0.54, p < 0.01$ (one-tailed)

The **affective responsiveness** domain was also significantly correlated with **depression** scores for relatives:

$R = 0.67, p < 0.01$ (one tailed)

Elective Cardiac Sugery Patients:

None of the FAD domains was significantly correlated with anxiety.

However, the following domains were significantly correlated with **depression**:

Problem Solving: $r = 0.53, p < 0.05$

Communication: $r = 0.61, p < 0.01$

Roles: $r = 0.55, p < 0.05$

Affective Involvement: $r = 0.48, p < 0.05$

Elective Cardiac Surgery Relatives:

Affective involvement was significantly correlated with **anxiety**:

$R = 0.51, p < 0.05$

The following domains correlated significantly with relatives **depression**:

Problem Solving: $r = 0.57, p < 0.05$

Communication: $r = 0.64, p < 0.01$

Roles: $r = 0.54, p < 0.05$

Affective responsiveness: $r = 0.54, p < 0.05$

TESTING THE RESEARCH MODEL

The original research model put forward at the end of the introduction was tested using a linear regression model. Gender and the post-hoc measure of family functioning difference were also added in to the model. Due to the small numbers being entered for the analysis (N = 35), the significant family functioning domains from the post-hoc analysis were not added in to the model. This was to avoid introducing more error. The new model that was put forward for testing is shown in Figure 8.

As the research questions did not aim to establish linearity both family functioning and psychological adjustment were alternately used as the dependent variables.

Testing the model in this way hoped to answer the following questions.

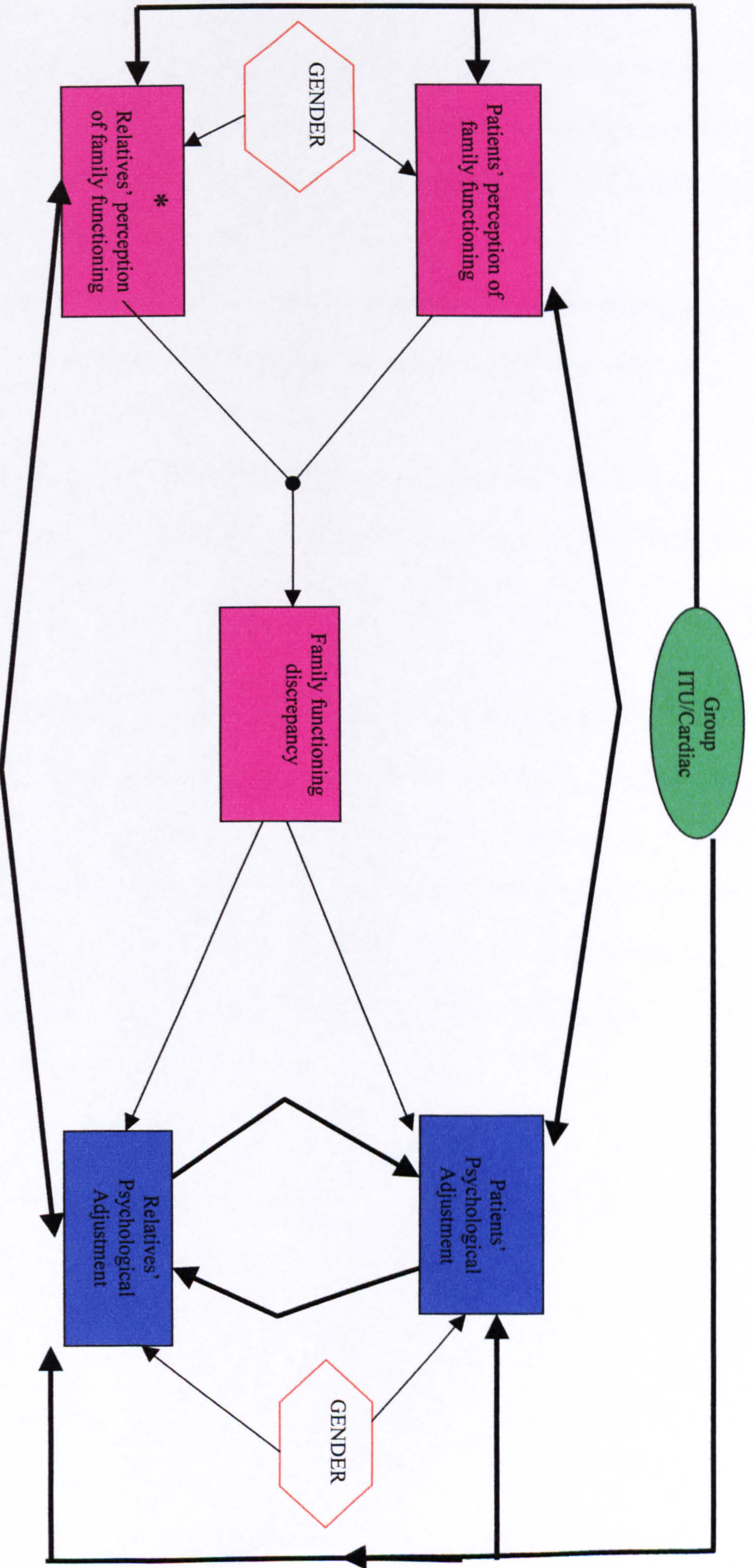
Do any of the models factors contribute significantly to the variance in patients' and relatives' psychological adjustment?

Do any of the models' factors contribute significantly to the variance in patients' and relatives' perceived family functioning?

The testing of the model in this way was used for exploratory purposes only and as a guide for future research recommendations.

R squared calculates the amount of the independent variables variance explained by the model. R squared values range from 0 – 1, with 1 explaining all of the variance.

FIGURE 8: Revised research model



A stepwise multiple linear regression analysis was computed. Anxiety and depression were entered first as the dependent variables and separate analyses were computed for patients and relatives. The N for each analysis was therefore 35. The models factors were entered in the following order:

Gender, Group (ITU/Elective cardiac surgery), General family functioning score, Family functioning difference score, relatives' psychological adjustment.

For patients none of the models' factors explained a significant amount of the variance in anxiety or depression and therefore all variables were removed by the regression analysis.

However for relatives the factor of general family functioning accounted for a significant amount of the variance in both anxiety and depression. All of the other factors in the model were removed from the analysis. The results of the analysis for relatives is shown in Tables 17 and 18. General family functioning explains 19.8% of the variance in relatives' anxiety scores (Table 17). General family functioning accounts for an even larger amount of the variance in relatives' depression scores, with 39.1% being explained (Table 18).

Table 17: Stepwise Multiple Linear Regression Findings For Relatives, Using Anxiety as the Dependent Variable

Variables Explaining A Significant Amount Of The Variance:	R-SQUARE	ADJUSTED R-SQUARE (%)	F	P	BETA	T
General functioning	0.22	19.8	9.39	0.004	0.47	3.07

Table 18: Stepwise Linear Regression Findings Using Relatives Depression as The Dependent Variable

Variables Explaining A Significant Amount Of The Variance:	R-SQUARE	ADJUSTED R-SQUARE (%)	F	P	BETA	T
General Functioning	0.41	39.10	22.82	0.00	0.64	4.78

For the linear regression using the family functioning score as the dependent variable, the variables were entered in the following order:

Gender, Group, depression and anxiety.

A separate analysis was calculated for patients' and relatives' family functioning scores.

The results of this analysis are shown in Table 19, below. As was the case with patients' psychological adjustment scores, none of the factors in the model significantly predicted patients' perceptions of family functioning. However, a significant amount of the variance in relatives' perceptions of family functioning was explained by depression (39.1%).

Table 19: Stepwise Multiple Linear Regression Findings Using Relatives Perceptions of Family Functioning As The Dependent Variable

Variables Explaining A Significant Amount Of The Variance	R-SQUARE	ADJUSTED R-SQUARE (%)	F	P	BETA	T
Depression	0.41	39.10	22.82	0.00	0.64	4.78

SPECIFIC ITU RELATED QUESTIONS

Research Question 4: Do ITU patients and relatives differ in how ill they remember themselves/their relative being while they were in intensive care? Do differing perceptions of illness severity impact on psychological adjustment?

Hypothesis E

There will be a significant difference in patients' and relatives' perception of severity of illness while in ITU.

This hypothesis was tested by computing a paired samples t-test. This test calculates if the paired differences between variables are significant. Table 20, shows the results of this analysis.

As can be seen from Table 20, the difference between patients' and relatives' illness severity score is a significant one, where relatives' scores are significantly higher than patients'. Therefore hypothesis E is accepted.

Table 20: Paired Samples T-Test Analysis Between Patients And Relatives

Perceptions Of Illness Severity While In ITU

	Paired differences				
	Mean	SD	T	df	Significance (2-tailed)
Patients' illness severity score – relatives illness severity score	-3.70	6.79	-2.44	19	0.025*

*The difference is significant at the $p < 0.05$ level

Hypothesis F

There will be a positive relationship between the difference score of severity of illness and psychological adjustment of patients and relatives.

The difference score (patients' illness severity score – relatives' illness severity score) was computed. A negative score indicates that the relative recalls the patient as having been more seriously ill than the patient. These scores were then correlated with psychological adjustment in both patients and relatives to see if a greater discrepancy between patient and relative resulted in poorer psychological adjustment. This was calculated using a partial correlation, controlling for the effects of gender.

Both relatives' and patients' anxiety and depression scores were not significantly related to the difference score. Hypothesis F was therefore rejected.

DISCUSSION

This study aimed to establish if ITU patients and their closest relatives were a unique sample by comparison with an elective cardiac surgery group, while also investigating the role of family factors (family functioning and relatives' adjustment) in psychological adjustment. A specific ITU question was also addressed to establish the validity of claims that patients and relatives differ in their recollection of illness severity and that this can lead to tension during the recovery period. A discussion of the main findings in relation to the studies research questions follows below. This is followed by a consideration of the clinical implications of the research, discussion of methodological issues and research implications and recommendations.

INTERPRETATION OF FINDINGS

Research Question 1: Are ITU patients and their relatives a unique sample of medical patients?

Claims that ITU patients are 'unique' are not supported by the findings of the present study. ITU patients and elective cardiac surgery patients did not differ significantly across any of the main study variables (anxiety, depression and family functioning).

Literature discussed in the introduction, has found that patients' perceptions of family functioning does not differ across illness specialities (Arpin et al., 1990). Based on these findings the research hypotheses in the present study predicted that there would be no group differences in family functioning. The present findings support the hypothesis and the findings of Arpin et. al. (1990) as patients did not differ across the

groups on any of the variables. Likewise, psychological adjustment has been found to be unrelated to illness type or severity (Grossman, 1995; Arpin et al., 1990). Given that patients did not differ in their psychological adjustment the findings support this previous research.

Interesting findings were found for the relatives in the two groups. ITU relatives reported significantly higher scores on the depression sub-scale of the HADS and also perceived their families functioning as significantly more unhealthy than elective cardiac surgery patients.

These statistical findings are supported by the qualitative findings of the open question ('What comes to mind when you think of life before ITU and now?') which was completed by the relatives. The themes which emerged from the ITU relatives were of a stronger nature than the elective cardiac surgery group, with relatives talking about the experience being "life-changing". Overall, there was a sense from the ITU relatives that the experience had been more traumatic. In comparison, elective cardiac surgery relatives reported more positive consequences of the surgery and discussed how they had been 'lucky' and now had a "better quality of life" to look forward to. Maybe it is this more profound nature which leads to greater scores on depression.

Qualitative information regarding relatives' experiences of the recovery period post-ITU is not apparent in the ITU literature. This study is therefore the first to formally document relatives' experiences through the use of empirical data, rather than authors' impressions. The findings from this qualitative analysis, along with the

quantitative findings discussed above may be useful in planning interventions with this group of patients and relatives.

Studies comparing relatives' perceptions of family functioning across illness specialities have not been carried out in the literature. It is therefore not possible to conclude if the difference found between ITU and elective cardiac surgery relatives' perceptions of family functioning is a typical finding across illness groups, or if it reflects that ITU relatives have unique experiences both during the ITU stay and recovery period.

Comparisons of ITU patients and relatives with other medical groups would need to be carried out before the claims about 'uniqueness' can be properly established. However what is emerging from these findings is that relatives appear to have a different experience to patients.

Research Question 2: What influence do family factors (family functioning and relatives' adjustment) have on psychological adjustment of patient and relative?

Neither general functioning or the general functioning difference score were significantly related to psychological adjustment in patients. This was the case for both ITU and elective cardiac surgery patients. The linear regression analysis for patients further supports these findings. None of the family factors inputted in to the model explained a significant amount of the variance.

The McMaster model of family functioning attempts to explain those elements of family functioning that are known to have most significance on problem areas such as psychological functioning. The lack of a significant relationship between general family functioning and adjustment amongst patients, suggests that general family functioning is not good at predicting psychological distress in patients. This is contrary to the rationale of the McMaster model. However, as was shown by the supplementary analysis of the FAD domains, although the general family functioning score was not related to psychological adjustment, some individual domains were related. For ITU patients problem solving was significantly correlated with anxiety and behaviour control with depression. In contrast, a larger number of FAD domains were significant for the elective cardiac surgery patients and were only significantly correlated with depression.

The finding that general family functioning is not related to adjustment but that more specific domains of family functioning are, may suggest that the role of family factors in patients' adjustment is more complicated and requires a more detailed analysis. The small numbers in the present study make it difficult to generalise or interpret the findings of the FAD domains. A larger study may well help to clarify this relationship further.

Findings for relatives are in contrast to patients, with both ITU and elective cardiac surgery relatives showing significant relationships between general family functioning and psychological adjustment. Significant relationships were shown for both anxiety and depression scores. Both ITU and elective cardiac surgery relatives also showed significant relationships between FAD domains and adjustment. For ITU relatives a

significant relationship was shown between the general functioning difference score and psychological adjustment. Again regression analysis supported these findings with general family functioning explaining a significant amount of the variance in both anxiety and depression for ITU and elective cardiac surgery relatives. It is possible, therefore to conclude that family functioning is an important factor in the prediction of psychological adjustment for relatives. The findings for the relatives are in support of the McMaster model as family functioning is associated with psychological distress. This is in accordance with the models predictions.

Comparison of the role of family factors in patients and relatives adjustment to ITU/elective cardiac surgery suggests that for relatives family functioning is a more important predictor in adjustment. Only a few domains of family functioning displayed significant relationships for patients and their importance remains confusing without confirmation from a larger study.

Models such as Crisis theory and Social support theory have been constructed to explain how patients adjust to illness. Models which attempt to explain relatives' adjustment do not appear in the literature. The present models do not help explain why patients' and relatives' adjustment are not related to the same factors. Clearly, different models are needed to account for this difference.

The possibility that different factors may contribute towards psychological adjustment in patients and relatives has been suggested elsewhere in the literature (Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; O'Farell and Murray, 2000; Purden, 1995). These studies have found physical factors, hopelessness, lower

education, uncertainty and personal support to be unique predictors of patients' distress and family functioning and support factors to be unique predictors of relatives' adjustment. The current studies findings are in agreement with this literature and support this as a valid area for future research.

One possible explanation for the finding that general family functioning is related to relatives' psychological adjustment but not patients' will now be offered. It may be that the recovery period carries different meanings for patient and relative. For patients, recovery is a physically demanding time and the focus is often on the self and getting better. A focus on the patient is also directed from outside of the family, with health professionals and well wishers enquiring about the patients' well-being. Less attention is generally paid to the relatives. The family's functioning may therefore represent the relatives key support system. For the carer/ relative, the well being of the family (i.e. family functioning) becomes their sole responsibility as patients are often too ill to take on this role. So, although the relatives' focus may also be on the patients' health, they also need to maintain the family's functioning. Maybe, if family functioning is unhealthy, this is more readily noticed by relatives. It is possible that this perception can lead to feeling unsupported or over-burdened which may lead to increased anxiety and depression. In contrast, patients may be less aware of the state of the family's functioning, due to their need to focus their attention inwards on themselves and their recovery. It may be then that patients are unable to make these more global appraisals or simply that it is not an important criteria on which to judge how well they are recovering.

Another hypothesis addressed in the present study was the relationship between patients' and relatives' anxiety and depression. It was hypothesised that patients' and relatives' adjustment would influence one another i.e. if the patient is depressed it is more likely that the relative will be depressed. This relationship has both support (Northouse, Dorris & Charron-Moore, 1995) and opposition in the literature (Northouse et al., 2000). In the present study patients' and relatives' adjustment scores were not significantly related. In fact examination of the descriptive data for patients' and relatives' anxiety and depression scores (Table 8) shows that a greater number of relatives than patients had borderline or clinically significant scores for anxiety and depression. The difference between patients' and relatives' psychological adjustment is most apparent in the ITU groups anxiety levels. Within the ITU group relatives are significantly more anxious than patients.

Patients amnesia for their time in ITU may explain this finding. It is possible that the relatives may feel alone in their memories of the ITU experience. The ITU memories may well be anxiety provoking resulting in an increased realisation of mortality and fears that the patient will die. This may explain the higher levels of anxiety in relatives. Another possible explanation are the meanings attached to the role of carer and patient. Often patients are protected and cared for by their relatives. It may be that the relatives role as carer includes protecting patients from potential anxieties. This and the view of the medical model that relatives are not in need of support may help explain why relatives are more anxious than patients.

This finding is not uncommon and many of the studies cited in the literature reported psychological distress in relatives which is greater or equal to patients' distress (Kaye

and Gracely, 1993; Omne-Ponten et al., 1993; Blanchard et al., 1997; Groom et al., 1998; Pakenham, 2001). These findings and their support in the present study contradict social support theories that a supportive relationship from someone who is themselves depressed or anxious will have a negative impact on the recipients own anxiety or depression. However, this provides further support for the notion that patients and relatives may have different experiences of the recovery period.

The prevalence rates in Table 8 were calculated so that comparison with previous ITU research could take place. In the present study 5% of ITU patients scored in the borderline or clinically significant range for anxiety. This compares with the previous figures from Manchester Royal infirmary (Eddleston et. al., 2000) of 11.9%.

Comparison of these two figures is however problematic as the Eddleston figure is calculated on the lower cut-off score of ≥ 8 . A recent article by Crawford et al (2001) suggested that the higher cut-off of >10 should be used, as normative data suggests it is more representative of epidemiological prevalence rates. Therefore, although the Eddleston figure is higher it may be that were the more conservative estimate used, the two figures would be more similar. The two other prevalence studies have calculated anxiety prevalence to be 33% at 6 months (Jones et al., 2001b) 46% at 2 months and 55.5% at 6 months (Jones et al., 1994a). The prevalence rates of anxiety for patients in the present study are therefore low in comparison to other studies.

These comparisons must be made with caution however due to the small sample size of the present study and the differing time points, cut-off's and measures used across the studies referenced.

Prevalence rates for patients' depression is also 5%. Again when comparing with the previous studies this is again lower. Eddleston et al. (2000) reported that 9.8% (at 3 months) of their patients were depressed. Jones et al. (2001b) reported higher prevalence rates of 12% (at 6 months).

Only anxiety figures are available for long term follow up in relatives. In the present study, 35% of ITU relatives scored within the clinical range for anxiety. This compares with Jones et al's (1999c) prevalence rates of 28% at 2 months and 32% at 6 months. Therefore, the relatives in the present study reported slightly higher levels of anxiety than previous research has shown.

Interpretation of the discrepancy in patients' prevalence rates between this study and previous research is limited by the small numbers. However, it raises the question again as to why prevalence rates may differ across studies and research centres. A valid area for future research would be to investigate why these differences exist.

Research Question 3: Do any of the research models factors explain a significant amount of the variance in psychological adjustment/family functioning?

The regression analysis was carried out to summarise the factors that have been explored in the results section and to test the significance of the research model. In order to account for previous criticism of research being uni-directional, both adjustment (anxiety and depression) and family functioning were entered as the dependent variable to test if the direction of relationships explained differing amounts of variance. The revised research model stated that the following factors may explain anxiety and depression in patients and relatives:

Gender, group (i.e. whether they are from the ITU or cardiac group), family functioning, family functioning difference score, and the relatives' adjustment. It therefore combined the first two research questions in to one model.

The testing of the model in this way is not robust and the analysis was computed for solely exploratory purposes. The findings however were interesting. As discussed earlier, the model was a weak predictor of adjustment in patients, and it may be that other factors are more important in explaining patients' anxiety and depression. The model however was a better predictor of relatives' anxiety and depression. The general family functioning factor explained a significant amount of the variance in both relatives' anxiety and depression. This factor is therefore a targetable area for intervention in relation to relatives' anxiety and depression. When using family functioning as the dependent variable, only depression explained a significant amount of the variance. It is interesting that the relationship between anxiety and family functioning was not bi-directional. However it may follow that the negative perceptions which are characteristic of depressive thinking styles affect perceptions of family functioning, but that the catastrophic thinking styles characteristic of anxiety do not affect perceptions of family functioning. Another hypothesis may be that anxious people continue to function whereas depressed people may not and that this may impact on how they perceive their family's functioning. Exploring the regression analysis in this way confirms the need to think systemically about adjustment in general as is advocated by such models as the biopsychosocial model and Crisis Theory.

Research Question 4: Do patients and relatives differ in their recollections of ITU illness severity and does this difference impact on psychological adjustment?

The specific ITU research question hoped to address statements in the literature that patients and relatives differ in their perceptions of illness severity and that this may lead to tensions during the recovery period (Griffiths et al.,1996). Although there was a significant difference between patients' and relatives' perceptions of illness severity, this difference was not significantly related to psychological adjustment. The present findings therefore provide empirical evidence for claims in the literature that this difference in perceptions exists. However the differing perceptions do not cause such tensions that they result in adjustment difficulties. It may be that the discrepancy in illness severity may influence adjustment through mediating factors which were not investigated in the present study, or that the small sample size of the present study, did not allow for this relationship to be expressed. The role of mediating factors was not considered in the design of the present study. However were this study to be replicated it would be interesting to consider testing models which incorporate mediating factors and consider if family functioning may be mediating the relationship between illness severity perception and adjustment. Further research in to this would need to be carried out to conclude the importance of this factor for ITU patients' and relatives' adjustment.

CLINICAL IMPLICATIONS OF THE RESEARCH

Probably the most useful finding from the present project is the high scores for relatives. This highlights the psychological needs of relatives and suggests that they are equal to, or greater than that of the patient. Clinically, this finding has large implications for ITU practices. Follow-up groups are largely run for patients and only assess the patients' adjustment. Relatives will often accompany patients and will undoubtedly benefit from having patient problems identified, receiving appropriate support resources and having common patient problems normalised. However their own experiences will not be normalised and neither will their psychological adjustment be assessed. Clearly these relatives are experiencing high levels of anxiety and depression and also require a service to address their needs.

Although the clinical implications discussed so far have focused on ITU practices, the findings may also have more far reaching implications. The elective cardiac surgery relatives also reported more anxiety and depression and it may be that more general health services should also be addressing follow-up care for relatives as well as patients. A more systemic model of health care for adult physical services is required where relatives and families can be more involved.

The high anxiety experienced by relatives is in many ways a 'normal' reaction which most patients described as 'ebbing away' with time. It is unlikely then that this group of people require intensive, long term interventions. Referring on to primary care services would be unlikely to meet this groups needs, and the specialist nature of ITU may not be understood by colleagues working outside of this field. It is interesting

that when offered a referral to primary care services, relatives often refused this. At the point of follow-up relatives would be likely to benefit from a non-stigmatising and easily accessible normalising intervention, similar to what the patients receive and some short term supportive counselling.

The finding that a significant amount of the variance in psychological adjustment is explained by family functioning provides a clear avenue for targeting interventions for relatives. Helping families to increase healthy aspects of their family functioning and reduce the unhealthy aspects should reduce psychological distress. As well as providing an intervention at the point of follow-up, as already discussed, a preventative approach could also be utilised. Prior to patients being discharged home, the FAD could be administered to detect those families with unhealthy family functioning. It follows from the findings, that those families with unhealthy family functioning will contain relatives who are at risk of psychological distress during the recovery period. These families could then receive some preventative interventions to reduce possible adjustment difficulties. The domains of the FAD would help clinicians to identify which areas of family functioning require intervention. The intervention may involve supportive counselling or family therapy.

Another, maybe less costly intervention could be the provision of a tentative psychological formulation to the family. The information that is available from ITU clinicians' knowledge base, McMaster Theory, information gleaned from the themes of the open question and results of the FAD could be combined to provide individual formulations for each family. This could describe to families problems they may incur during the recovery period and suggest problem solving skills and practical support

systems they could use to overcome these difficulties. Extra psychological and practical support could then be provided if problems arise.

The advantage of a preventative approach is the ability to provide psychological frameworks and support in a non-stigmatising and easily accessible way. As discussed before, existing referral pathways for relatives through primary care were not taken up by relatives and this may be due to stigma and myths surrounding seeking help from a psychologist. Clearly, support is needed for this group of relatives and patients and it may be that novel service provision may need to be created to provide psychological support that is accessible.

METHODOLOGICAL CONSIDERATIONS

There are some methodological issues in the present study which may provide alternative explanations for some of the results discussed above. These will now be discussed below along with some general criticisms and strengths of the current study.

SAMPLE CHARACTERISTICS

Small Sample Sizes

Many of the conclusions drawn from the present study are hindered due to the small sample size. The small numbers make it difficult to generalise the findings from this sample of ITU and cardiac patients to all cardiac and ITU patients. A larger sample would have allowed greater confidence in making such generalisations. This issue was discussed earlier in relation to the question surrounding the uniqueness of ITU patients.

Voluntary Samples

Both the experimental and comparison group made use of a voluntary sample. People who volunteer to take part in research are argued to have differing characteristics to non-volunteers, such as being easy to engage and eager to help. This can lead to a biased sample (Rosnow & Rosenthal, 1976). Therefore the sample used in the present study could be argued to be unrepresentative of the population of ITU and cardiac patients. This again makes generalisations of findings difficult. Volunteer bias in the ITU sample may have been partly overcome by the fact that the research was constructed around an already existing ITU follow-up clinic. Therefore participants were not going 'out of their way' to volunteer. Even taking this in to account, those individuals who do not attend their clinic appointment are still left as the 'unknown'

in both research and follow-up protocols. Although the sample of ITU patients may be slightly more representative of the 'average' ITU patient, this does not follow for the elective cardiac surgery patients. These patients were not attending an already existing follow-up clinic, and were therefore a true volunteer sample. It may be that this discrepancy in volunteer status explains the differences found between relatives in the two groups. It could be argued that the cardiac patients and relatives who consented represented those families who have fewer problems and are easier to engage.

Gender Bias

The sample did suffer from a gender bias, in that the average patient was male and the average relative female. The possible contamination that this may cause in the results and interpretations was however controlled for by partialling out for the effects of gender in the analyses. The groups were also matched on gender and this eliminated contamination of data in the group differences analyses. This is therefore a strength of the study which will be discussed further in the consideration of the studies research design.

RECRUITMENT

Both postal and ward recruitment were used in the present study. These differing methods of recruitment have obvious problems in that it may make replication difficult. Unfortunately limited time and practical constraints led to these differing methods being used.

MEASURES

Another possible criticism of the present study is the sole use of the HADS as a measure of psychological adjustment. Ideally, the researcher would have liked to have used other measures of adjustment to account for problems such as PTSD, hypochondriasis and social withdrawal. This could have occurred with a more general screening measure such as the GHQ or the SCL-90. Unfortunately, it was not possible to give patients any more measures to complete, due to the fact that they were already completing a battery of measures for the follow-up clinic. The research was therefore limited by clinical restraints. Again, however this could be viewed as a strength, in that it makes the research more clinically valid and viable.

This criticism can also be applied to the omission of the open question to patients.

Again this occurred due to constraints on patients' time.

While carrying out the research it became apparent through discussions with the relative, that in some of the cases the anxiety and depression which was being reported was not indicative of ITU related distress but of other ongoing life events. Research prior to this study has assumed that elevated HADS scores indicate ITU related distress (Eddleston et al., 2000; Jones et al., 2001b). They do not discuss how the elevated score could also be a reflection of other psychological issues which are separate to ITU. It may be that a psychological interview is needed to accompany these scores. This would enrich our understanding of why scores are elevated and if indeed the proportion of ITU related psychological difficulties are as high as reported. This may well have already been considered in the above studies but no discussion of this issue is incorporated in to the their discussions.

ANALYSIS

The multiple linear regression analysis was used to summarise the results. This analysis was purely exploratory, due to the limitations of the small sample size. It is therefore open to the possibility of error, particularly given that the dependent variable was rotated to allow for the exploration of a bi-directional relationship. The findings were however interesting and focused the recommendations for future research.

RESEARCH DESIGN

A potential criticism of the design is the omission of a normative group to act as a 'control' group. Given the time constraints for data collection, it was not possible to include a third group. The measures used in the research also provide normative data. Therefore it is possible to compare the two groups FADS and HADS scores with an already established normative group. For these reasons a 'normal' control group was not felt necessary.

Despite the discussed limitations with the present study, it is felt that there are also several strengths. A comparison group has not been utilised before in the ITU literature and this study is therefore the first. Future research may benefit from further comparisons with other medical specialities. Another strength of the study is that the participants were matched across the two groups. This and the controlling of gender through statistics made the findings more robust. The design of the study was very much led by criticisms of previous research and is also theory driven.

RESEARCH IMPLICATIONS

The findings of the present study lend further support to the small body of research which has addressed the need of the relative.

Further research is needed to address why ITU relatives are more depressed and perceive their family functioning as more unhealthy. Is it that ITU relatives are a unique sample, rather than patients. If so, why? Further exploration of factors unique to the ITU experience, such as the role of amnesia and hallucinations would need to be addressed to further consider this question of uniqueness.

The findings of this study further reiterates that relatives also suffer psychological adjustment difficulties. The finding that family functioning was an important predictor of relatives' adjustment but not patients' is not a new finding. However the body of research which has reported the same findings is still very small. Further replication of this study and others is needed to validate claims that different mechanisms may operate to explain patients' and relatives' adjustment.

Possible explanations as to why family functioning may be more important for relatives' than patients' adjustment have been tentatively hypothesised in this discussion section. However, in order to develop models which can guide clinicians understanding and interventions with patients and relatives, future research will need to address and explore why this difference in importance exists. It may be that initial qualitative analysis exploring patients' experiences of the recovery period as well as

the relative will help in forming some hypotheses to help develop models of adjustment to then test.

The idea that patients' and relatives' adjustment needs may be different is an aspect that is not covered in health psychology texts. The findings of the present study suggest that relatives and the family experience should be given a greater emphasis in individual health psychology practice. Clearly, further research is needed to explore what these different factors and models may be.

It would be interesting to look at the role of family functioning and cognitive factors together, to gauge how much of the variance in adjustment each of the factors explains or adds to the explanation of variance. Examination of cognitive factors would be particularly interesting given that during the recovery period patients often suffer from temporary cognitive difficulties such as poor memory and concentration. Research addressing these factors would begin to test the crisis theory model and see how well it explains adjustment in patients and relatives. Such research may help establish if these health psychology models designed for patients are also applicable to relatives.

Although the current project was not directly related to cardiac patients, an interesting theme which emerged from their open question analysis was the psychological impact of having the operation cancelled, both for patients and relatives. This was mentioned by several participants. It would be interesting to investigate how a cancellation interferes with peoples' (patients' and relatives') cognitive preparation for an operation, procedural anxiety and subsequent physical and psychological adjustment.

In terms of methodological implications for future research, the researcher would recommend that comparisons of ITU groups with other medical specialities continues, using matched designs. Future research should also aim to gather larger samples. It may be beneficial to gather a wider assessment of psychological adjustment, using a more general scale such as the GHQ, accompanied by a clinical interview. This would help to ascertain those psychological difficulties that are ITU related and non-ITU related. Most importantly, future research should be guided by theories such as the biopsychosocial model and crisis theory to allow continued consideration of bi-directional relationships and systemic thinking.

CONCLUSION

In conclusion, the present study has demonstrated that relatives' anxiety and depression is often greater than that of patients. It could also be suggested from this study that ITU relatives are a unique sample due to their significantly higher depression scores and perceptions of more unhealthy family functioning. Future research is called for to continue investigating if ITU relatives have a 'unique' experience and if so, why this difference may be.

The role of family functioning in relatives' psychological adjustment has been implicated but not however for patients. This discrepancy in factors which predict adjustment in patients and relatives has been discussed and it has been recommended that future research should attempt to replicate these findings and design models which account for these differences.

Clinically the research has large implications, highlighting the need for a service to address relatives' needs as well as patients. The role of family functioning in relatives' adjustment also leads to clearly targetable areas for interventions which have been discussed.

Although the study has limitations, it is felt that it also has several strengths. Hopefully, the study should open up further avenues for exploring relatives' psychological adjustment and stimulate research in to models which may account for the differing explanations of adjustment between patient and relative.

REFERENCES

Akamatsu, T.J., Stephens, M.A.P., Hobfoll, S.E. & Crowther, J.H. (Eds.) (1992).

Family Health Psychology. London: Hemisphere Publishing Corporation.

Armstrong, A.E. (2001). The Impact of Parent-adolescent attachment, social support, and development on adjustment to cancer. Dissertation Abstracts International:

Section B – The Sciences and Engineering, 61, 6695.

Aronson, E., Wilson, T.D., and Akert, R.M. (1997). Social Psychology, 2nd ed. New York: Longman.

Arpin, K., Fitch, M., Browne, G.B. & Corey, P. (1990). Prevalence and Correlates of family dysfunction and adjustment to illness in speciality clinics. Journal of Clinical Epidemiology, 43, 373-383.

Barnhill, L. & Longo, D. (1978). Fixation and regression in the family life cycle. Family Process, 17, 469-478.

Beavers, W.R. & Hampson, R.B. (1990). Successful Families: Assessment and Intervention. New York: W.W. Norton.

Berkman, L., & Syme, S. (1979). Social networks, host resistance, and mortality: A nine year follow-up study of Alameda County residents. American Journal of Epidemiology, 2, 186-204.

Berkman, L.F. (2000). Social support, social networks, social cohesion, and health. Social Work in Health Care, 31, 3-14.

Bishop, D.S., Epstein, N.B., Baldwin, L.M. & Miller, I.W. (1988). Older couples: The effect of health, retirement and family functioning on morale. Family Systems Medicine, 6, 238-247

Blanchard, C.G., Albrecht, T.L. & Ruckdeschel, J.C. (1997). The Crisis of cancer: Psychological impact on family caregivers. Oncology (Huntington), 11, 189-194.

Bohachick, P. & Anton, B.B. (1990). Psychosocial adjustment of patients and spouses to severe cardiomyopathy. Research in Nursing and Health, 13, 385-392.

Breu, C. & Dracup, K. (1978). Helping the spouses of critically ill patients. American Journal of Nursing, 78, 50-53.

Briggs, D. (1991). Preventing ICU Psychosis. Nursing Times, 87, 30-31.

Brown, J.S., Rawlinson, M.E. & Hardin, D.M. (1982). Family functioning and health status. Journal of Family Issues, 3, 91-110.

Campbell, T.L. (1986). Family's impact on health: A critical review. Family Systems Medicine, 4, 135-200.

Carter, G.A. & McGoldrick, M. (1980). The Family Life Cycle: A Framework for Family Therapy. New York: Gardner Press

Christenson, A.J., Turner, C.W., Slaughter, J.R. & Holman, J.M. (1989). Perceived family support as a moderator of psychological well-being in end stage renal disease. Journal of Behavioral Medicine, 12, 249-265.

Cohen, S.M. & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98, 310-357.

Compton, P. (1991). Critical illness and intensive care: What it means to the client. Critical Care Nurse, 11, 50-56.

Crawford, J.R., Henry, J.D., Crombie, H.C., & Taylor, E.P. (2001). Normative data for the HADS from a large non-clinical sample. British Journal of Clinical Psychology, 40, 429-434.

Danielson, C.B., Hamel-Bissel, B. & Winstead-Fry, P. (1993). Families, Health and Illness: Perspectives on Coping and Intervention. London: Mosby.

Department of Health. (2000). Comprehensive critical care: Review of adult critical care services. Department of Health.

Derogatis, L.R. & Lopez, M.C. (1983). PAIS and PIAS-R Scoring Manual I.

Baltimore: John Hopkins University, School of Medicine.

DiMatteo, M. & Hays, R. (1981). Social support and serious illness. In: Gottlieb, B. (ed.) Social Networks and Social Support. Beverley Hills, CA: Sage.

Drewniak, T.A. (2001). The effect of social support and health behaviour on psychosocial adjustment of coronary heart disease patients. Dissertation Abstracts International: Section A – Humanities and Social Sciences, 61, 3905.

Eddleston, J.M., White, P., & Guthrie, E. (2000). Survival, morbidity and quality of life after discharge from intensive care. Critical Care Medicine, 28, 2293-2299.

Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. Science, 196, 129-136.

Epstein, N.A., Bishop, D.S., & Levin, S. (1978). The McMaster model of family functioning. Journal of Marital and Family Counselling, 4, 19-31.

Epstein, N.B., Baldwin, L.M., & Bishop, D (1983). The McMaster Family Assessment Device. Journal of Marital and Family Therapy, 9, 171-180.

Epstein, N.B., & Bishop, D.S. (1981). Problem centered systems therapy of the family. In: Gurman, A.S. & Kniskern, D.P. (eds.). Handbook of Family Therapy. New York: Guilford Press.

Epstein, N.B., Bishop, D., Ryan, C., Miller, I., & Keitner, G. (1993). The McMaster model view of healthy family functioning. In Walsh, F. (Ed.). Normal Family Processes (2nd ed.) p.138-160. New York: Guilford Press.

EuroQol Group (1990). EuroQol - a new facility for the measurement of health-related quality of life. Health Policy, 16, 199-208.

Fisher, M.E., & Moxham, P.A. (1984). ICU syndrome. Critical Care Nurse, 4, 39-46.

Fobair, P. A., & Zabora, J. R. (1995). Family functioning as a resource variable in psychosocial cancer research: Issues and measures. Journal of Psychosocial Oncology, 13, 97-114.

Foss, K.R. & Tenholder, M.F. (1993). Expectations and needs of persons with family members in an intensive care unit as opposed to a general ward. Southern Medical Journal, 86, 380-384.

Friedman, L. C., Baer, P. E., Nelson, D. V., Lane, M., Smith, F. E., & Dworkin, R. J. (1988). Women with breast cancer: Perception of family functioning and adjustment to illness. Psychosomatic Medicine, 50, 529-540.

Gelling, L. (1999). Causes of ICU psychosis: the environmental factors. Nursing in Critical Care, 4, 22-26.

Granberg, A., Bergbom-Engberg, I.E., & Lundberg, D. (1996). Intensive care syndrome: a literature review. Intensive and Critical Care Nursing, 14, 294-307.

Griffiths, R.D. & Jones, C. (1999). ABC of intensive care: Recovery from intensive care. British Medical Journal, 319, 427-429.

Griffiths, R.D., Jones, C., MacMillan, R.R. (1996). Where is the harm in not knowing? Care after intensive care. Clinical Intensive Care, 7, 144-145.

Groom, K.N., Shaw, T.G., O'Connor, M.E., Howard, N.I. & Pickens, A. (1998). Neurobehavioural symptoms and family functioning in traumatically brain-injured adults. Archives of Clinical Neuropsychology, 13, 695-711.

Grossman, M. (1995). Received support and psychological adjustment in critically injured patients and their family. Journal of Neuroscience Nursing, 27, 11-23.

Gruen, W. (1975). Effects of brief psychotherapy during the hospitalisation period on the recovery process in heart attacks. Journal of Consulting and Clinical Psychology, 43, 223-232.

Haley, J. (1976). Problem Solving Therapy. New York: Harper and Row.

Hansell, H.N. (1984). The behaviour and effects of noise on man: The patient with ICU psychosis. Heart and Lung, 13: 59-65.

Hermann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale – A review of validation data and clinical results. Journal of Psychosomatic Research, 42, 17-41.

Horwarth, E., & Weissman, M.M. (1995). Epidemiology of depression and anxiety disorders. In Tsuang, M.T., Tohen, M., & Zahner, G.E.P. (Eds.). Textbook in Psychiatric Epidemiology. New York: Wiley

Johnson, S., Craft, M., Titler, M., & Halm, M. (1995). Perceived changes in adult family members roles and responsibilities during critical illness. Journal of Nursing Scholarship, 27, 238-243.

Jones, C. & Griffiths, R.D. (1995). Social support and anxiety levels in relatives of critically ill patients. British Journal of Intensive Care, Feb., 44-47

Jones, C., Griffiths, R.D., & Humphris, G. (1999a). Factual memories of intensive care may reduce anxiety post-ICU. British Journal of Anaesthesia, 82: 739

Jones, C., Griffiths, R.D. & Humphris, G. (1999b). Relatives are still very anxious two weeks after patients intensive care discharge. British Journal of Anaesthesia, 82: 797

Jones, C., Griffiths, R.D. & Humphris, G. (2000). Disturbed memory and amnesia related to intensive care. Memory, 8, 79-94.

Jones, C., Griffiths, R.D., Humphris, G., Skirrow, P. (2001a). Memory, delusions and the development of acute post-traumatic stress disorder-related symptoms after intensive care. Critical Care Medicine, 29, 573-580.

Jones, C., Griffiths, R.D., MacMillan, R.R. & Palmer, T.E.A. (1994a). Psychological problems occurring after intensive care. British Journal of Intensive Care, Feb., 46-53.

Jones, C., Humphris, G.M., & Griffiths, R.D. (1998). Psychological morbidity following critical illness – the rationale for care after intensive care. Clinical Intensive Care, 9, 199-205.

Jones, C., Macmillan, R.R., & Griffiths, R.D. (1994b). Providing psychological support for patients after critical illness. Clinical Intensive Care, 5, 176-179.

Jones, C. & O'Donnell, C. (1994). After intensive care – What then? Intensive and Critical Care Nursing, 10, 89-92.

Jones, C., Skirrow, P., Griffiths, R.D., Humphris, G., Dawson, S., Eddleston, J. (1999c). Predicting intensive care relatives at risk of post-traumatic stress disorder. Presented to the Intensive Care Society (ICS), London, 9-10, Dec.

Jones, C., Skirrow, P., Griffiths, R.D., Humphris, G., Dawson, S., White, P., Eddleston, C., Walmann, C., Gager, M. (2001b). A randomised controlled trial of rehabilitation following critical illness. Intensive care medicine, 27, S240.

Jones, J., Hoggart, B., Withey, J., Donaghue, K. & Ellis, B.W. (1979). What the patients say: A study of reactions to an intensive care unit. Intensive Care Medicine, 5, 89-92.

Kabakoff, R.I., Miller, I.W., Bishop, D.S., Epstein, N.B., & Keitner, G.L. (1990). A psychometric study of the McMaster Family Assessment Device in psychiatric, medical and non-clinical samples. Journal of Family Psychology, 3, 431-439.

Kaye JM; Gracely EJ (1993) Psychological distress in cancer patients and their spouses. Journal of Cancer Education, 8: 47-52

Kleeman, K.M. (1989). Families in crisis due to multiple trauma. Critical Care Nurse Clinics of North America, 1, 23-31.

Kleiber, C., Halm, M., Titler, M., Montgomery, L.A., Johnson, S.K., Nicholson, A., Craft, M., Buckwalter, K. & Megivern, K. (1994). Emotional responses of family members during a critical care hospitalisation. American Journal of Critical Care, 3, 70-76.

Knaus, W.A., Draper, E.A., Wagner, D.P. & Zimmerman, J.E. (1985). APACHE-II: A severity of disease classification system. Critical Care Medicine, 13, 818-829.

Koshy, G., Wilkinson, A., Harmsworth, A. & Waldman, C.S. (1997). ICU follow-up programme at a district general hospital. Intensive Care Medicine, 23, S160.

Kreamer, C.L. (1990). The relationship of family functioning, family demographics, and severity of illness to family coping with the crisis of critical illness. Dissertation Abstracts International, 50, 4453-4454.

Laitinen, H. (1996). Patients experience of confusion in the intensive care unit following cardiac surgery. Intensive and critical care nursing, 12, 79-83.

Landsman, I.S., Baum, C.G., Arnkoff, D.B., Craig, M.J., Lynch, I., Copes W.S. & Champion, H.R. (1990). The psychosocial consequences of traumatic injury, Journal of Behavioral Medicine, 13, 561-581.

Leach, L.R., Frank, R.G., Bouman, D.E. and Farmer, J. (1994). Family functioning, social support and depression after traumatic brain injury. Brain Injury, 8, 599-606.

Leske, J.S. & Jiricka, M.K. (1998). Impact of family demands and family strengths and capabilities on family well-being and adaptation after critical injury. American Journal of Critical Care, 7, 383-392.

Littlefield, C.H., Rodin, G.M., Murray, M.A., & Craven, J.L. (1990). Influence of functional impairment and social support on depressive symptoms in persons with diabetes. Health Psychology, 9, 737-749.

MacKellaig, J.M. (1990). A review of the psychological effects of intensive care on the isolated patient and his family. Care of the Critically Ill, 6, 100-102.

Manne, S.L. & Zautura, A.J. (1989). Spouse criticism and support: Their association with coping and psychological adjustment among women with rheumatoid arthritis. Journal of Personality and Social Psychology, 56, 608-617.

Mayou, R., Foster, A. & Williamson, B. (1978). The psychological and social effects of myocardial infarction on wives. British Medical Journal, 1, 699-701.

McCubbin, H.I., & Patterson, J.M. (1983). Family transitions: adaptation to stress. In McCubbin, H.I., & Figley, C.R. (Eds.). Stress and the Family: Volume 1: Coping with Normative transitions. New York: Bruner/Mazel

McCubbin, H.I., Olson, D.H. and Larson, A.S. (1981). Family Crisis Oriented Personal Evaluation Scales (F-COPES). In: McCubbin H.I., Thompson, A.I. (Eds.) Family Assessment Inventories for Research and Practice. Madison, Wis.: University of Wisconsin-Madison; 1991:203-216

McGuire, B.E., Basten, C.J. Ryan, J.R. & Gallagher, J. (2000). Intensive care unit syndrome – a dangerous misnomer. Archives of Internal Medicine, 160, 906-909.

Miller, I.W., Epstein, N.B., Bishop, D.S. & Keitner, G.I. (1985). The McMaster Family Assessment Device: Reliability and validity. Journal of Marital and Family Therapy, 11, 345-356.

Miller, I., Ryan, C.E., Keitner, G.I., Bishop, D.S. & Epstein, N.B. (2000). The McMaster approach to families: theory, assessment, treatment and research. Journal of Family Therapy, 22, 168-189.

Minnes, P., McShane, J., Forkes, S., Green, S., Clement, B. & Card, L. (1989). Coping resources of parents of developmentally handicapped children living in rural communities. Australia and New Zealand Journal of Developmental Disabilities, 15, 109-118.

Minuchin, S. (1974). Families and Family Therapy. Cambridge, MA: Harvard University Press.

Molassiotis, A., Van den Akker, O.B.A. & Boughton, B.J. (1997). Perceived social support, family environment and psychosocial recovery in bone marrow transplant long-term survivors. Social Science Medicine, 44, 317-325.

Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B., & Bliss, J. (1991). The factor structure and factor stability of the Hospital Anxiety and Depression Scale in patients with cancer. British Journal of Psychiatry, 158, 255-

Moos, R.H. (1982). Coping with acute health crises. In: Millon, T., Green, C. & Meagher, R. (eds.). Handbook of Clinical Health Psychology. New York: Plenum.

Newman, B. & Newman, P. (1991). Development through life, 5th ed. Pacific Grove, CA: Brooks Cole.

Northouse, L.L., Dorris, G. & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. Social Science and Medicine, 41, 69-76.

Northouse, L. L., Jeffs, M., Cracchiolo-Caraway, A., Lampman, L., & Dorris, G. (1995). Emotional distress reported by women and husbands prior to a breast biopsy. Nursing Research, 44, 196-201.

Northouse, L.L., Mood, D., Templin, T., Mellon, S. & George, T. (2000). Couples' patterns of adjustment to colon cancer. Social Science and Medicine, 50, 271-284.

Nunnally (1978). Psychometric Theory (2nd Edition). New York: McGraw-Hill.

Nuttall, G.A., Kumar, M. & Murray, J.M. (1998). No difference exists in the alteration of circadian rhythm between patients with and without intensive care unit psychosis. Critical Care Medicine, 26, 1351-1355.

O'Farrell, P., Murray, J. & Hotz, S.B. (2000). Psychologic distress among spouses of patients undergoing cardiac rehabilitation. Heart and Lung the Journal of Acute and Critical Care, 29, 97-104.

Olson, D.H., Sprenkle, D., & Russell, C. (1979). Circumplex model of marital and family systems: I. Cohesion and adaptability dimensions, family types and clinical applications. Family Process, 18, 3-28.

Olson, D. (2000). Cicumplex model of marital and family systems. Journal of Family Therapy, 22, 144-167.

Omne-Ponten, M., Holmberg, L., Bergstrom, R., Sjoden, P.O. & Burns, T. (1993). Psychosocial adjustment among husbands of women treated for breast cancer; mastectomy vs. breast conserving surgery. European Journal of Cancer, 29A, 1393-1397.

Pakenham, K.I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. Psychology, Health and Medicine, 6: 13-27.

Peterson, C.D. (1998). Adjustment in chronically ill adolescents. Dissertation Abstracts International: Section B – The Sciences and Engineering, 59, 884.

Pistrang, N. & Barker, C. (1995). The partner relationship in psychological response to breast cancer. Social Science and Medicine, 40, 789-797.

Pless, I.B. & Satterwhite, B. (1973). A measure of family functioning and its applications. Social Science and Medicine, 7, 613-621.

Pressman, M.R., Meyer, T.J., Peterson, D.D., Greenspon, L.W. & Figueroa, W.G. (1997). Effects of hospitalisation, surgery and anaesthesia on sleep and biological rhythms. In: Pressman, M.R. & Orr, W.C. Understanding Sleep. London: American Psychological Association.

Ptacek, J.T., Smith, R.E. & Zanas, J. (1992). Gender, appraisal and coping: A longitudinal analysis. Journal of Personality, 60, 747-770.

Purden, M.A. (1995). Wives' marital role and psychosocial adjustment: a study of patient and spouse outcomes two months after a myocardial infarction. McGill University, Doctoral Dissertation – research (403p.).

Registrar General's Standard Occupational Classification (2000). Volume 1. OPCS, HMSO, London.

Reider, J.A. (1989). The relationship of family needs satisfaction and family coping strategies to family adjustment during the critical illness of a family member. Dissertation Abstracts International. 50, 1858.

Reifman, A. (1995). Social relationships, recovery from illness and survival: A literature review. Annals of Behavioral Medicine, 17, 124-131.

Roberts, S.B., Bonnici, D.M., Mackinnon, A.J. & Worcester, M.C. (2001). Psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) among female cardiac patients. British Journal of Health Psychology, 6, 373-383

Rodrigue, J.R. & Park, T.L. (1996). General and illness-specific adjustment to cancer: Relationship to marital status and marital quality. Journal of Psychosomatic Research, 40, 29-36.

Rolland, J.S. (1993). Mastering family challenges in serious illness and disability. In Walsh, F. (Ed.). Normal Family Processes (2nd ed.). New York: Guilford Press.

Rook, K.S. (1984). The negative side of social interaction: Impact on psychological well-being. Journal of personality and Social Psychology, 46, 1097-1108.

Rosnow, R.L. & Rosenthal, R. (1976). The Volunteer subject revisited. Australian Journal of Psychology, 28, 97-108.

Sarafino, E.P. (1998). Health Psychology: Biopsychosocial Interactions (3rd ed.). New York: John Wiley and Sons, Inc.

Schelling, G., Stoll, C., Meier, M., Haller, M., Briegel, J., Manert, W., Hummel, T., Lenhart, A., Heyduck, M., Polasek, J., Meier, M., Preuß, U., Bullinger, M., Schuffel, W. & Peter. (1998). Health related quality of life and post-traumatic stress disorder in survivors of adult respiratory distress syndrome. Critical Care Medicine, 26, 651-659.

Schlosser, B. (1990). The assessment of subjective well-being and its relationship to the stress process. Journal of Personality Assessment, 54, 128-140.

Schwabb, R.J. (1994). Disturbances of sleep in the intensive care unit. Critical Care Clinics, 10, 681-694.

Schwartz, L. & Kraft, G.H. (1999). The role of spouse responses to disability and family environment in multiple sclerosis. American Journal of Physical Medicine and Rehabilitation, 78, 525-532.

Sitzman, B.T. (1993). ICU psychosis: Organic, psychosocial or both? Psychiatric Forum, 16, 33-39.

Skirrow, P., Jones, C., Griffiths, R.D. & Kaney, S. (2001). Intensive care – easing the trauma. The Psychologist, 14, 640-642.

Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In: Murray, M. & Chamberlain, K. Qualitative Health Psychology – Theories and Methods. London: SAGE Publications.

Soar, J. (1999). Psychological aspects of critical care. In: Craft, T.M., Nolan, J.P. and Parr, M.J.A. Key Topics in Critical Care. Padstow: BIOS Scientific Publishers Ltd.

Soellner, W., Zschocke, I., Zing-Schir, M., Stein, B., Rumpold, G., Frish, P. & Augustin, M. (1999). Interactive patterns of social support and individual coping strategies in melanoma patients and their correlation's with adjustment to illness. Psychosomatics, 40, 239-250.

Spiegel, D., Bloom, J.R. & Yalom, I. (1981). Group support for patients with metastatic cancer. A randomised prospective outcome study. Archives of General Psychiatry, 38, 527-533.

Spiegel, D., Bloom, J. R., & Gottheil, E. (1983). Family environment as a predictor of adjustment to metastatic breast carcinoma. Journal of Psychosocial Oncology, 1, 33-44

Spielberger, C. (1987). Manual for the State-Trait Anxiety Inventory. Consulting Psychologists Press.

Steele, S. (1998). Breast cancer: Psychosocial adjustment and health outcomes. Dissertation Abstracts International: Section B – The Sciences and Engineering, 58, 5156.

Sykes, D.H., Hanley, M., Boyle, D.M., Higginson, J.D.S. & Wilson, C. (1999). Socio-economic status, social environment, depression and postdischarge adjustment of the cardiac patient. Journal of Psychosomatic Research, 46, 83-98.

Tess, M.M. (1991). Acute confusional states in critically ill patients: A review. Journal of Neuroscience Nursing, 23, 393-402.

Turner, J.S., Briggs, S.J., Sprighorn, H.E., Potgeiter, P.D. (1990). Patients recollection of intensive care unit experience. Critical Care Medicine, 18, 966-968.

Twibell, R.S. (1998). Family coping during critical illness. Dimensions of Critical Care Nursing, 17, 100-112.

Ussher, J.M. Gender Issues and Womens Health. In: Baum, A., Newman, S., Weinman, J., Weist, R., & McManus, C. (Eds.). (1997). Cambridge Handbook of Psychology, Health and Medicine. Cambridge University Press. Cambridge

Veit, C. & Ware, J. (1983). The structure of psychological distress and well-being in general populations. Journal of Consulting and Clinical Psychology, 51, 730-742.

Ware JJ, Sherbourne CD. (1992)The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Medical Care, 30, 473-83.

Westley, W.A. & Epstein, N.B. (1969). The Silent Majority. San Francisco: Jossey-Bass.

White, N.E., Richter, J.M. & Fry, C. (1992). Coping, social support and adaptation to chronic illness. Western Journal of Nursing Research, 14, 211-224.

Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale, Acta Psychiatrica Scandinavica, 67, 361-70

APPENDIX 1

EXPERIMENTAL GROUP: CONSENT OBTAINED ON WARD PRIOR TO DISCHARGE HOME

PATIENT INFORMATION SHEET

When the patient returns home from ICU: Effects on relatives and patients.

You are being invited to take part in a research study.

It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why research on ICU patients and their relatives?

It is becoming more apparent to people working in Intensive Care Units (ICU) that the patients and relatives of ICU patients understandably experience a great deal of stress when the patient is in the ICU. However little is known about the stresses experienced when the patient returns home and is recovering. Little is known about how families cope and feel when the relative returns home.

The present research hopes to address these issues. Approximately 60 ICU patients and their relatives will be asked to participate in this research. With your help we can hopefully provide future ICU patients and families with the correct support when they leave ICU.

What will be asked of you?

You will have already received a visit from a nurse from ICU who will have invited you to attend a follow up clinic 3 months after your discharge to home. This is a routine follow up clinic which all patients are invited to attend. At this clinic, patients' progress is reviewed.

However at present, only the patients are interviewed. Often relatives feel that they have a lot to say and have concerns and worries of their own that they would like to share. We are asking for relatives to also attend the follow up clinic.

At the follow up clinic, you will be asked to complete some questionnaires with the ICU follow-up nurse. The questionnaires look at how you and your family have been feeling and coping since discharge from ICU. At the same time, your relative will be completing questionnaires in an adjacent room with the researcher. It is anticipated that appointments will last for approximately one hour.

What will happen to your information?

Patient questionnaires are already part of an ongoing follow up clinic, and information obtained from the questionnaires will be shared with the follow up clinic. Information that you share with the researcher will be confidential. Instances when confidentiality

is broken are when there are concerns about your own or someone else's welfare. Otherwise information is completely confidential.

Your GP will be informed of your involvement in the research. Once the questionnaires are completed they will be used to better inform clinicians of how patients and relatives feel and cope when the patient returns home from the ICU.

It is anticipated that this research will be published in a research journal. No names or identifying information will be used in this publication. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed.

What if you do not want to take part?

Taking part in the research is entirely voluntary. If you decide not to take part it in no way affects your access to any treatments or your rights to take part in the follow up clinic. This will go ahead as usual and the researcher will not use any of your information obtained at the follow up appointment.

What happens now if you decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, **please complete the attached consent form and place it along with your relatives in the envelope provided. The follow-up nurse will collect the envelope before you are discharged home from the ward.**

After the consent forms have been returned, you will be visited or telephoned by the researcher who will introduce herself, answer any questions you may have and arrange a time and date for the follow up clinic. A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and answer any questions you may have.

What if you change your mind?

You are perfectly free to do this and withdraw from the research at any time. It will not affect any treatment or care given. You will still be able to attend the follow up group and not take part in the research.

How can you contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 2

EXPERIMENTAL GROUP: CONSENT OBTAINED ON WARD PRIOR TO DISCHARGE HOME

CLOSEST RELATIVE INFORMATION SHEET

When the patient returns home from ICU: Effects on relatives and patients.

You are being invited to take part in a research study.

It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why research on ICU patients and their relatives?

It is becoming more apparent to people working in Intensive Care Units (ICU) that the patients and relatives of ICU patients understandably experience a great deal of stress when the patient is in the ICU. However little is known about the stresses experienced when the patient returns home and is recovering. Little is known about how families cope and feel when the relative returns home.

The present research hopes to address these issues. Approximately 60 ICU patients and their relatives will be asked to participate in this research. With your help we can hopefully provide future ICU patients and families with the correct support when they leave ICU.

What will be asked of you?

As you will probably be aware, patients who have been in ICU are invited to attend a follow-up clinic to monitor progress since discharge. This is a routine follow up clinic which all patients are invited to attend. This takes place 3 months after patients are discharged from ICU.

Normally, only ICU patients are invited to attend the follow up group. Often relatives feel that they have a lot to say and have concerns and worries of their own that they would like to share. We are asking for the patient's **closest relative** to also attend the follow up clinic.

At the follow up clinic, you will be asked to complete some questionnaires with the researcher which look at how things have been since the return home. Likewise, your relative will be asked to complete questionnaires in an adjacent room with the ICU follow-up nurse. It is anticipated that the appointment will last for approximately one hour.

What will happen to your information?

All relatives' questionnaires will be anonymised. This means that it will not be possible to identify your responses as belonging to you. Information that you share with the researcher will be confidential. Instances when confidentiality is broken are

when there are concerns about your own or someone else's welfare. For communication purposes your GP will be informed of your involvement in the research, although your answers will not be shared with him/her.

Once the questionnaires are completed they will be used to better inform clinicians of how patients and relatives feel and cope when the patient returns home from the ICU.

It is anticipated that this research will be published in a research journal. No names or identifying information will be used in this publication. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed.

What if you do not want to take part?

Taking part in the research is entirely voluntary and you should not feel obliged to do so.

What happens now if you decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, please complete the attached consent form. *The consent form should then be placed along with your relatives consent form in the envelope provided. The follow-up nurse will collect the envelope at a later date before you leave the ward.* As soon as the researcher receives your consent forms she will attempt to contact you to further discuss the research and clarify any questions you may have. At this point an appointment will be made for the follow up clinic. A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and answer any questions you may have.

What if you change your mind?

You are perfectly free to do this and withdraw from the research at any time.

How can you contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 3a

CONSENT FORM – PATIENT

Research Title:

When the patient returns home from ICU: Effects on family and patient

Name of Researcher: Ellen Young (Trainee Clinical Psychologist)

PLEASE CIRCLE THE APPROPRIATE RESPONSES BELOW:

I confirm that I have read and understood the attached information sheet

YES

NO

I have asked any questions that I have about the study

YES

NO

I understand that I am free to withdraw from the study at any time, and that my medical care and legal rights will not be affected

YES

NO

I give permission for my medical notes to be examined

YES

NO

I agree to take part in the study

YES

NO

Name of patient:

Date:

Signature:

Name of closest relative:

Date:

Signature:

CONTACT TELEPHONE NUMBER:

Researcher

Ellen Young
(Trainee Clinical Psychologist)

Date

Signature:

APPENDIX 3b

CONSENT FORM – RELATIVE

Research Title:

When the patient returns home from ICU: Effects on family and patient

Name of Researcher: Ellen Young (Trainee Clinical Psychologist)

PLEASE CIRCLE THE APPROPRIATE RESPONSES BELOW:

I confirm that I have read and understood the attached information sheet

YES

NO

I have asked any questions that I have about the study

YES

NO

I understand that I am free to withdraw from the study at any time.

YES

NO

I agree to take part in the study

YES

NO

Name of patient:

Date:

Signature:

**Name of closest relative:
(main caregiver)**

Date:

Signature:

CONTACT TELEPHONE NUMBER:

Researcher:

Ellen Young
(Trainee Clinical Psychologist)

Date:

Signature:

APPENDIX 4

CONTACT INFORMATION SHEET

NAME:

AGE:

D.O.B:

GENDER:

OCCUPATION:

LENGTH OF ICU STAY:

LENGTH OF WARD STAY:

APACHE SCORES:

PRESENTING ILLNESS:

PREVIOUS ILLNESS HISTORY:

HOME ADDRESS:

CONTACT TELEPHONE NUMBER:

CLOSEST RELATIVES NAME:

RELATIVES AGE:

RELATIVES OCCUPATION:

RELATIVES CONTACT NUMBER:

OTHER RELEVANT INFORMATION:

APPENDIX 5

EXPERIMENTAL GROUP: CONSENT TO BE OBTAINED VIA POST AFTER DISCHARGE HOME

PATIENT INFORMATION SHEET

When the patient returns home from ICU: Effects on relatives and patients.

You are being invited to take part in a research study. It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why research on ICU patients and their relatives?

It is becoming more apparent to people working in Intensive Care Units (ICU) that the patients and relatives of ICU patients understandably experience a great deal of stress when the patient is in the ICU. However little is known about the stresses experienced when the patient returns home and is recovering. Little is known about how families cope and feel when the relative returns home.

The present research hopes to address these issues. Approximately 60 ICU patients and their closest relative (i.e. Main caregiver) have been asked to participate in this research. With your help we can hopefully provide future ICU patients and families with the correct support when they leave ICU.

What will be asked of you?

You will have already received a visit from a nurse from ICU who will have invited you to attend a follow up clinic 3 months after your discharge to home. This is a routine follow up clinic which all patients are invited to attend. At this clinic, patients' progress is reviewed.

However at present, only the patients are interviewed. Often relatives feel that they have a lot to say and have concerns and worries of their own that they would like to share. We are asking for relatives to also attend the follow up clinic.

At the follow up clinic, you will be asked to complete some questionnaires with the ICU follow-up nurse. The questionnaires look at how you and your family have been feeling and coping since discharge from ICU. At the same time, your relative will be completing questionnaires in an adjacent room with the researcher. It is anticipated that appointments will last for approximately one hour.

What will happen to your information?

Patient questionnaires are already part of an ongoing follow up clinic, and information obtained from the questionnaires will be shared with the follow up clinic. Information that you share with the researcher will be confidential. Instances when confidentiality

is broken are when there are concerns about your own or someone else's welfare. Otherwise information is completely confidential.

Your GP will be informed of your involvement in the research. Once the questionnaires are completed they will be used to better inform clinicians of how patients and relatives feel and cope when the patient returns home from the ICU.

It is anticipated that this research will be published in a research journal. No names or identifying information will be used in this publication. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed.

What if you do not want to take part?

Taking part in the research is entirely voluntary. If you decide not to take part it in no way affects your access to any treatments or your right to take part in the follow up clinic. This will go ahead as usual and the researcher will not use any of the patient's information.

What happens now if you decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, please complete the attached consent form and return it in the stamped-addressed envelope provided. If you have further questions please feel free to contact the researcher on one of the telephone numbers below.

A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and answer any questions you may have.

What if you change your mind?

You are perfectly free to do this and withdraw from the research at any time. It will not affect any treatment or care given.

How can you contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 6

EXPERIMENTAL GROUP: CONSENT TO BE OBTAINED VIA POST AFTER DISCHARGE HOME

CLOSEST RELATIVE INFORMATION SHEET

When the patient returns home from ICU: Effects on relatives and patients.

You are being invited to take part in a research study.

It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why research on ICU patients and their relatives?

It is becoming more apparent to people working in Intensive Care Units (ICU) that the patients and relatives of ICU patients understandably experience a great deal of stress when the patient is in the ICU. However little is known about the stresses experienced when the patient returns home and is recovering. Little is known about how families cope and feel when the relative returns home.

The present research hopes to address these issues. Approximately 60 ICU patients and their closest relative (i.e. Main caregiver) have been asked to participate in this research. With your help we can hopefully provide future ICU patients and families with the correct support when they leave ICU.

What will be asked of you?

As you will probably be aware, patients who have been in ICU are invited to attend a follow-up clinic to monitor progress since discharge. This is a routine follow up clinic which all patients are invited to attend. This takes place 3 months after patients are discharged from ICU.

Normally, only ICU patients are invited to attend the follow up clinic. Often relatives feel that they have a lot to say and have concerns and worries of their own that they would like to share. We are asking for the patient's **closest relative** to also attend the follow up clinic.

At the follow up clinic, you will be asked to complete some questionnaires with the researcher which look at how things have been since the return home. Likewise, your relative will be asked to complete questionnaires in an adjacent room with the ICU follow-up nurse. It is anticipated that the appointment will last for approximately one hour.

What will happen to your information?

All relatives' questionnaires will be anonymised. This means that it will not be possible to identify your responses as belonging to you. Information that you share with the researcher will be confidential. Instances when confidentiality is broken are

when there are concerns about your own or someone else's welfare. For communication purposes your GP will be informed of your involvement in the research, although your answers will not be shared with him/her.

Once the questionnaires are completed they will be used to better inform clinicians of how patients and relatives feel and cope when the patient returns home from the ICU.

It is anticipated that this research will be published in a research journal. No names or identifying information will be used in this publication. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed.

What if you do not want to take part?

Taking part in the research is entirely voluntary and you should not feel obliged to do so.

What happens now if you decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, please complete the attached consent form and return it in the stamped-addressed envelope provided. If you have further questions please feel free to contact the researcher on one of the telephone numbers below.

A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and answer any questions you may have.

What if you change your mind?

You are perfectly free to do this and withdraw from the research at any time.

How can you contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 7

PATIENT INFORMATION SHEET

When the Patient Returns home from the Intensive Care Unit (ICU): Effects on Relatives and Patients.

- Do intensive Care Unit Patients and their Relatives Adapt to the Illness Experience Differently to Elective Cardiac Patients and Their Families?

You are being invited to take part in a research study.

It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why am I being invited to take part in this research

The main aim of the present research is to determine how families function and cope when the patient returns home from a stay of more than 24 hours in the Intensive care unit. However part of this study also hopes to address whether the coping and functioning of ICU families is unique or whether it is just a result of the experience all families have when a family member has been ill and is recovering. Therefore we need to compare the findings from the ICU population with another medical group who will act as the 'control' group. For the purposes of this study 60 elective cardiac surgery patients and their closest relative will be asked to participate.

What will I be asked to do?

You will be invited to attend a follow up clinic three months after you have been discharged home from hospital. Both the patient and their closest relative will be invited to attend. At the follow up clinic you will be asked to complete a few questionnaires which look at how you are feeling and how your family is functioning and coping since the return home from hospital. The researcher will also see your relative separately who will complete similar questionnaires. It is anticipated that the appointment will last for approximately an hour and a half.

How will my information be used?

The information you provide us with will allow us to establish if the findings from the intensive care population are unique findings or if they are due to a more general effect such as the illness experience.

Your GP will be informed of your involvement in the study, but your answers will not be shared with him/her. All questionnaires will be anonymised. This means that it will not be possible to identify your responses as belonging to you. Information that you share with the researcher will be confidential and will not be discussed with other professionals outside of the study. Instances when confidentiality is broken are when there are concerns about your own or someone else's welfare. Otherwise information is *completely confidential*.

Once the study is complete the findings will be written up in a journal article. However it will not be possible to identify your own responses, as they will be anonymised. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed. It may be that this information will help to better inform practice with cardiac patients when they return home from hospital.

What if I do not want to take part?

Taking part in the research is entirely voluntary. If you decide not to take part it in no way affects your access to any treatments.

What happens now if I decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, please complete the attached consent form and return it in the stamped addressed envelope provided. In a few days time you will be contacted by the researcher who will introduce herself, answer any questions you may have and arrange a time and date for the follow up clinic. A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and to ask any questions you may have.

What if I change my mind?

You are perfectly free to do this and withdraw from the research at any time. It will not affect any treatment or care given.

How can I contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 8

CLOSEST RELATIVE INFORMATION SHEET

When the Patient Returns home from the Intensive Care Unit (ICU): Effects on Relatives and Patients.

- Do intensive Care Unit Patients and their Relatives Adapt to the Illness Experience Differently to Elective Cardiac Surgery Patients and Their Families?

You are being invited to take part in a research study.

It is important that you are aware of why the research is being carried out and what it will involve. Please read the following and take time to read and discuss it. Feel free to contact the researcher and ask any questions on the telephone number below.

Why am I being invited to take part in this research

The main aim of the present research is to determine how families function and cope when the patient returns home from a stay of more than 24 hours in the Intensive care unit. However part of this study also hopes to address whether the coping and functioning of ICU families is unique or whether it is just a result of the experience all families have when a family member has been ill and is recovering. Therefore we need to compare the findings from the ICU population with another medical group who will act as the 'comparison group'. For the purposes of this study 60 elective cardiac surgery patients and their closest relative will be asked to participate.

What will I be asked to do?

You will be invited to attend a follow up clinic with your relative, 3 months after they have been discharged from hospital. The researcher will complete questionnaires with you which will look at how your family has been feeling and coping since returning home from hospital. Your relative will be seen separately from you and will also complete similar questionnaires. It is anticipated that the appointment will take approximately an hour and a half.

How will my information be used?

The information you provide us with will allow us to establish if the findings from the intensive care population are unique findings or if they are due to a more general effect such as the illness experience.

Your GP will be informed of your involvement in the study, but your answers will not be shared with him/her. All questionnaires will be anonymised. This means that it will not be possible to identify your responses as belonging to you. Information that you share with the researcher will be confidential and will not be discussed with other professionals outside of the study. Instances when confidentiality is broken are when there are concerns about your own or someone else's welfare. Otherwise information is completely confidential.

Once the study is complete the findings will be written up in a journal article. However it will not be possible to identify your own responses, as they will be anonymised. A copy of the journal article can be forwarded to you on its completion, if you wish. Once this article has been submitted all of your data will be destroyed. It may be that this information will help to better inform practice with cardiac patients when they return home from hospital.

What if I do not want to take part?

Taking part in the research is entirely voluntary and you should not feel obliged to do so.

What happens now if I decide to take part?

If you are happy with the information you have been provided with and would like to take part in the research, please complete the attached consent form and return it in the stamped addressed envelope provided. In a few days time you will be contacted by the researcher who will introduce herself, answer any questions you may have and arrange a time and date for the follow up clinic. A week or so before the follow up appointment, you will be contacted by phone to confirm your attendance and to ask any questions you may have.

What if I change my mind?

You are perfectly free to do this and withdraw from the research at any time.

How can I contact the researcher?

The researcher's name is Ellen Young and she can be contacted at any time throughout the study on the following numbers:

0161 2768742

0161 2764603

APPENDIX 9

Registrar Generals' Standard Occupational Classification 2000 (SOC2000)

MAJOR GROUPS:

- 1 Managers and Senior Officials**
- 2 Professional Occupations**
- 3 Associate Professional and Technical Occupations**
- 4 Administrative and Secretarial Occupations**
- 5 Skilled Trades Occupations**
- 6 Personal Service Occupations**
- 7 Sales and Customer Service Occupations**
- 8 Process, Plant and Machine Operatives**
- 9 Elementary Occupations**



Hospital Anxiety and Depression Scale

Name	Date
------------	------------

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

fold along dashed line

A

3

2

1

0

D

0

1

2

3

A

3

2

1

0

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)



HOSPITAL ANXIETY AND DEPRESSION SCALE

D	
0	
1	
2	
3	
	A
	3
	2
	1
	0
D	
3	
2	
1	
0	
	A
	0
	1
	2
	3
D	
3	
2	
1	
0	
	A
	0
	1
	2
	3

fold along dashed line

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

(continued overleaf)



HOSPITAL ANXIETY AND DEPRESSION SCALE

D	
3	
2	
1	
0	
	A
	3
	2
	1
	0
D	
0	
1	
2	
3	
	A
	3
	2
	1
	0
D	
0	
1	
2	
3	
	A
	3
	2
	1
	0
D	
0	
1	
2	
3	
	A
	3
	2
	1
	0
D	
0	
1	
2	
3	
	A
	3
	2
	1
	0

fold along dashed line

I have lost interest in my appearance:

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things:

- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Now check that you have answered all the questions

For office use only:

D : Borderline 8-10

A : Borderline 8-10

© Zigmond and Snaith, 1983. From 'The Hospital Anxiety and Depression Scale,' *Acta Psychiatrica Scandinavica* 67, 361-70. Reproduced by kind permission of Munksgaard International Publishers Ltd, Copenhagen.

This measure is part of *Measures in Health Psychology: A User's Portfolio*, written and compiled by Professor Marie Johnston, Dr Stephen Wright and Professor John Weinman. Once the invoice has been paid, it may be photocopied for use **within the purchasing institution only**. Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 4920 03 4



APPENDIX 11

1. Planning family activities is difficult because we misunderstand each other.
_____SA _____A _____D _____SD _____

2. We resolve most everyday problems around the house.
_____SA _____A _____D _____SD _____

3. When someone is upset the others know why.
_____SA _____A _____D _____SD _____

4. When you ask someone to do something, you have to check that they did it.
_____SA _____A _____D _____SD _____

5. If someone is in trouble, the others become too involved.
_____SA _____A _____D _____SD _____

6. In times of crisis we can turn to each other for support.
_____SA _____A _____D _____SD _____

7. We don't know what to do when an emergency comes up.
_____SA _____A _____D _____SD _____

8. We sometimes run out of things that we need.
_____SA _____A _____D _____SD _____

9. We are reluctant to show our affection for each other.
_____SA _____A _____D _____SD _____

10. We make sure members meet their family responsibilities.
_____SA _____A _____D _____SD _____

11. We cannot talk to each other about the sadness we feel.

_____SA _____A _____D _____SD

12. We usually act on our decisions regarding problems.

_____SA _____A _____D _____SD

13. You only get the interest of others when something is important to them.

_____SA _____A _____D _____SD

14. You can't tell how a person is feeling from what they are saying.

_____SA _____A _____D _____SD

15. Family tasks don't get spread around enough.

_____SA _____A _____D _____SD

16. Individuals are accepted for what they are.

_____SA _____A _____D _____SD

17. You can easily get away with breaking the rules.

_____SA _____A _____D _____SD

18. People come right out and say things instead of hinting at them.

_____SA _____A _____D _____SD

19. Some of us just don't respond emotionally.

_____SA _____A _____D _____SD

20. We know what to do in an emergency.

_____SA _____A _____D _____SD

21. We avoid discussing our fears and concerns.

_____SA _____A _____D _____SD

22. It is difficult to talk to each other about tender feelings.

_____SA _____A _____D _____SD

23. We have trouble meeting our bills.

_____SA _____A _____D _____SD

24. After our family tries to solve a problem, we usually discuss whether it worked or not.

_____SA _____A _____D _____SD

25. We are too self-centered.

_____SA _____A _____D _____SD

26. We can express feelings to each other.

_____SA _____A _____D _____SD

27. We have no clear expectations about toilet habits.

_____SA _____A _____D _____SD

28. We do not show our love for each other.

_____SA _____A _____D _____SD

29. We talk to people directly rather than through go-betweens.

_____SA _____A _____D _____SD

30. Each of us has particular duties and responsibilities.

_____SA _____A _____D _____SD

31. There are lots of bad feelings in the family.

_____SA _____A _____D _____SD

32. We have rules about hitting people.

_____SA _____A _____D _____SD

33. We get involved with each other only when something interest us.

_____SA _____A _____D _____SD

34. There's little time to explore personal interests.

_____SA _____A _____D _____SD

35. We often don't say what we mean.

_____SA _____A _____D _____SD

36. We feel accepted for what we are.

_____SA _____A _____D _____SD

37. We show interest in each other when we can get something out of it personally.

_____SA _____A _____D _____SD

38. We resolve most emotional upsets that come up.

_____SA _____A _____D _____SD

39. Tenderness takes second place to other things in our family.

_____SA _____A _____D _____SD

40. We discuss who is to do household jobs.

_____SA _____A _____D _____SD

41. Making decisions is a problem for our family.

_____SA _____A _____D _____SD

42. Our family shows interest in each other only when they can get something out of it.

_____SA _____A _____D _____SD _____

43. We are frank with each other.

_____SA _____A _____D _____SD _____

44. We don't hold to any rules or standards.

_____SA _____A _____D _____SD _____

45. If people are asked to do something, they need reminding.

_____SA _____A _____D _____SD _____

46. We are able to make decisions about how to solve problems.

_____SA _____A _____D _____SD _____

47. If the rules are broken, we don't know what to expect.

_____SA _____A _____D _____SD _____

48. Anything goes in our family.

_____SA _____A _____D _____SD _____

49. We express tenderness.

_____SA _____A _____D _____SD _____

50. We confront problems involving feelings.

_____SA _____A _____D _____SD _____

51. We don't get along well together.

_____SA _____A _____D _____SD _____

52. We don't talk to each other when we are angry.

_____SA _____A _____D _____SD _____

53. We are generally dissatisfied with the family duties assigned to us.

_____SA _____A _____D _____SD

54. Even though we mean well, we intrude too much into each others lives.

_____SA _____A _____D _____SD

55. There are rules about dangerous situations.

_____SA _____A _____D _____SD

56. We confide in each other.

_____SA _____A _____D _____SD

57. We cry openly.

_____SA _____A _____D _____SD

58. We don't have reasonable transport.

_____SA _____A _____D _____SD

59. When we don't like what someone has done, we tell them.

_____SA _____A _____D _____SD

60. We try to think of different ways to solve problems.

_____SA _____A _____D _____SD

APPENDIX 12

SEVERITY OF ILLNESS CONTINUUM

PLEASE MAKE A MARK ON THE LINE BELOW TO SHOW HOW ILL YOU REMEMBER YOURSELF / YOUR RELATIVE BEING WHEN THEY WERE IN INTENSIVE CARE

**SLIGHTLY
ILL**

LIFE-THREATENING

A horizontal line with vertical end caps, intended for marking the severity of illness. The line is positioned between the 'SLIGHTLY ILL' and 'LIFE-THREATENING' labels.

APPENDIX 13

RESEARCH TIMELINE

SUMMER 2000

Literature review on ICU syndrome

Formation of ideas looking at individual patient

1. No factual memories > psychological problems (anxiety, PTSD)

Q. How do these patients make sense of this illness experience and process the trauma if they have no memory? (cf those with memories)

2. Drawing on health psychology literature and models and factors known to contribute to differences in adjustment, compare those that go on to develop psychological difficulties with those that don't e.g. social support, locus of control, search for meaning, illness beliefs, gender.

DECEMBER 2000

Met with Christina Jones (researcher)

to discuss research ideas.

JANUARY 2001

Met with director of ICU to discuss

possibility of doing research

JAN – MARCH 2001

Meetings with ICU follow-up team and

Psychiatrist to discuss ideas

Patients already spend 1hr completing questionnaires in clinic – suggest examine relatives (high levels of anxiety and depression noted, but little research)

APRIL 2001 – June 2001

**Reviewed literature on families and health
Interest in work on EE in schizophrenia patients, but measures require long training.
Instead look at family functioning and family coping to see how these impact upon psychological adjustment in both relative and patient.**

JULY 2001

Completion of ethics form and protocol

AUGUST (end of) 2001

**Submitted ethics approval (Manchester)
August meeting cancelled**

SEPTEMBER 2001 (end of)

Ethical approval pending changes

Mid OCTOBER 2001

Final ethical approval, chairs action

NOVEMBER 2001

Began recruitment

DECEMBER 2001

Saw first participants

MANCHESTER LOCAL RESEARCH ETHICS COMMITTEES

Telephone:

Fax:

Gateway House
Piccadilly South
Manchester
M60 7LP

e-mail: enq@manchester.nwest.nhs.uk
www.manchesterhealth.co.uk

24 October 2001.

Dear Miss Young

When the patient returns home from ICU: Family functioning, family coping and patient and relative psychosocial adjustment to the ICU experience

Thank you for your letter of 2 October 2001 together with supporting papers. I have considered the amendments and documentation submitted in response to the Ethics Committee's earlier review of your application on 24 September 2001. Acting on behalf of the Committee I am now able to confirm final ethical approval for the study. The study should be started within three years of the date on which LREC approval is given.

The following items have been reviewed in connection with the study: ethical application form; revised information sheets; and consent form.

Would you please note that granting of ethical clearance does not confer management approval for the study. This can only be given by your employing authority. If the study is to take place in the Central Manchester and Manchester Children's University Hospitals Manchester NHS Trust and you have not already done so, you must contact the Trust's Research and Development Office in order to gain approval from the Trust.

Insurance cover is required for investigators who hold a substantive or honorary appointment with the University of Manchester and are involved in research studies on volunteers. If a project has been approved by an LREC, it only needs to be reported to the Senate Ethics Committee, in order that cover can be provided.

You must notify any serious unexpected adverse events to the Ethics Committee. If any significant protocol amendments are proposed you must obtain prior approval from the Ethics Committee.

Researchers are required to monitor the progress of their studies and you are expected to regularly inform the Committee of the progress.

Finally, please ensure that you quote the Ethics Committee reference number given at the top of this letter in any future correspondence.

Yours sincerely,


Chairman