

**Stress, Coping and Health related Quality of Life in pre and post- Liver Transplant
Patients**

Clair Kelly

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Supervisor: Dr Garry Prentice

Head of Department: Dr Sinead Eccles

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Department of Psychology

DBS School of Arts

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Abstract

This study aimed to investigate health related quality of life and perceived stress in liver transplant patients and how they are influenced by coping strategies and demographic variables. The Short Form (SF-36) Health Survey (Ware and Sherbourne 1992), Perceived Stress Scale (Cohen 1983) and the BriefCOPE (Carver 1997) were used. A total of 46 (N=46) participants were recruited from a Liver Transplant Clinic. Twenty six (N=26) participants were post transplantation and 20 (N=20) were pre transplant. Post transplant patients had higher levels of Health related Quality of life in all domains. Levels of stress were higher than norms in both patient groups. Self-Blame, Humour and Acceptance were, negatively related to both physical and mental components of HRQoL

1.0 Introduction

“A Chronic illness is one in which a patient’s symptoms continue over a long term to impair his or her ability to continue with significant activities and normal routines.” (Shuman 1996 p 6) Chronically ill patients experience a number of physical, psychological and social impairments and for this reason it is suggested that a biopsychosocial approach (Engel 1977; 1980) should be embraced when considering patient assessment and care. Quality of Life research on many patient populations has produced findings that challenge the popular biomedical approach in terms of patient assessment and care. Liver transplantation is a well-established treatment of end stage liver disease. It aims not only to prolong survival, but also to improve quality of life (Kim 2000). But although it is often an essential, life-saving treatment, it is an overwhelming and frightening experience (Bean and Wagner 2006). According to Gutteling, Duivenvoorden, Buuschbach, de Man and Darlington (2010) these patients are exposed to potentially treatable psychological symptoms. To date there has been no published study which focuses on the psychosocial well-being of Irish liver transplant candidates and recipients. The current study aims to investigate the Quality of life and levels of perceived stress in patients attending a Liver Transplant Clinic in Ireland. It will take a biopsychosocial approach measuring physical, psychological and social variables.

1.1 Liver Transplantation in Ireland

It is estimated that 45-50 adults and 2-4 children will require a liver transplant annually in Ireland. The main indications for liver transplantation are Alcohol Related Liver Disease (ALD), Auto Immune Chronic Active Hepatitis (AICAH), Primary Biliary Cirrhosis (PBC), and Primary Sclerosing Cholangitis (PSC), but other conditions are also considered (Liver Unit SVUH Para 3-4). . Between 1993 and 2005, 67% of patients in the liver transplant clinic in ██████████ Hospital had alcoholic related illnesses (Liver Unit ██████████ fig

1.0). Liver transplantation is only considered when all other attempts at treatment have failed. The absolute contraindications to Liver transplantation are: Acquired Immune Deficiency Syndrome (AIDS), uncontrolled infection, malignancy, active substance abuse, medical non-compliance and irreversible brain injury (Killenberg & Clavien 2006, pp 7-10). Therefore candidates for liver transplants are expected to adhere to a strict medical regime.

The prevalence of liver transplantation in Ireland is expected to increase in the future for three reasons. Firstly the medical field are ever improving and the introduction of new drugs is making it a safer and more successful procedure. Secondly it is expected that the number of individuals who contracted Hepatitis C from contaminated blood products in Ireland will need liver transplants in the future (Liver Unit SVUH Para 3). Finally, the prevalence of Alcoholic Liver disease in Ireland has increased by 201% from 28.3 per 100,000 of population in 1995 to 85.1 per 100,000 of population in 2009. The most significant increase was seen in the 15-34 age groups, with the prevalence increasing by 275% (Mongan, McCormick, O'Hara, Smyth & Long, 2011). This increase in ALD could see a rise in the number of patients requiring transplantation in the future. These issues provide justification for the current study as increased demand in liver transplantation should be met with increased knowledge and expertise of psychosocial issues experienced by patients.

1.2 Health Related Quality of Life

There has been no generally accepted definition of Quality of Life, although researchers have been claiming to measure it for decades. In relation to health QOL is referred to as health related quality of life (HRQoL) and can be described as “optimum levels of mental, physical, role and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well being” (Bowling, 2001, p6). The term Health Related Quality of Life

refers to an individual's overall well-being in relation to their health status. Although its measurement is not globally standardised, it still remains an important tool in gaining an indication of patient's wellbeing. Assessing quality of life in chronically ill patients is important to measure the impact of the disease on the individual. While clinical information can tell healthcare professionals much about a patient's progress it does not allow for the phenomena that two patients with the same clinical criteria can have different responses to their illnesses. (Guyett, Feeney & Patrick 1993).

HRQoL is commonly assessed as a major outcome in clinical trials and considered with cure rate, clinical response and survival (Fayers & Bjordal 2001). QoL assessments have the potential to offer a more realistic comprehensive and informative approach towards patient assessment and care (Bishop 2005). Routine psychological evaluations of candidates for transplantation add information which is useful for patient selection and management. (Stilley, Miller & Tarter 1997) There is currently no standard procedure for assessing quality of life in Irish Liver transplant patients.

1.3 Health Related Quality of Life in Liver Transplant Patients

While on the waiting list for Liver transplantation, patients are subject to a number of physical, social and emotional impairments. Physical symptoms of chronic and end stage liver disease can cause severe limitations in patients. Wainwright (1997) lists these symptoms as nausea, itching, weight loss, jaundice, swollen abdomen, haematemesis (vomiting blood) and extreme tiredness or fatigue. Bodily pain can also limit physical function and vitality (Forsberg et al 1999) and patients with high levels of fatigue seem to be more vulnerable to emotional distress and are more likely to perceive that their quality of life has been negatively affected according to Blackburn, Freeston, Baker, Jones and Newton (2007). Limitations of

social and leisure activities, dietary restrictions, financial difficulties and anxiety related to the surgery are important factors during the waiting time (Santos Junior et al 2008). Withdrawal from social situations can be seen in pre transplant patients and while waiting to undergo transplantation, many patients withdraw from activities that they feel define who they are (Baker & McWilliam 2003, as cited in Killenberg & Klavien 2006). As well as the physical symptoms of disease, most patients with Chronic and End Stage Liver disease experience symptoms such as anxiety and depression (Dogar et al 2009). Liver transplant patients have been compared to other solid organ transplant recipients and have been shown to experience more impairment psychologically before the procedure, but show greater improvement after receiving a transplant. (Beilby, Moss-Morris & Painter 2003; Goetzmann et al 2006a; Langenbach, Schmeisser, Albus & Decker, 2008)

Starzl et al in 1979 claimed to have studied Quality of life in post-transplant patients. They concluded that quality of life ranges from poor to superior after liver transplantation. However this study measured only physical variables such as jaundice, using serum bilirubin levels, demographic variables such as employment status and psychiatric complications, which were commented on as “miscellaneous outcomes”. The study also did not use any self-report measures. Therefore this study was more a measurement of health status than of health related quality of life. However the developments of more sophisticated tools have since made assessing HRQoL more feasible. The current study will use a holistic approach to patient assessment, covering physical, psychological and social aspects of Quality of Life.

A number of recent studies (e.g. Younossi et al 2000; Ratcliffe et al 2002; Pérez-San-Gregorio, Martin-Rodriguez, Perez-Bernal & Maldonado 2010) have shown that liver transplant candidates report worse HRQoL than the general population. There have also been

a number of studies which have shown that patients perceive their quality of life to be higher after receiving a liver transplant organ (Kober, Kuchler, Broelsch, Kremer & Henne-Bruns 1990; Hicks, Larson & Ferrans 1992; Moore, Jones, Angus, Hardy & Burrows 1992; DeBona et al 2000; Moore, Jones & Burrows 2000). For example Moore et al (1992) found that not only did patients feel that their overall quality of life had improved after transplantation, they particularly experienced less psychological distress and improved social interactions. DeBona et al (2000) have also shown that quality of life increases in both physical and psychological domains within six months of undergoing liver transplantation. Perez-San-Gregorio et al (2010) compared Health Related Quality of life pre and post liver transplantation. They found that pre transplant patients had lower physical, psychological and social well-being. Also that post liver transplant patients enjoy more physical independence and can return to daily activities and become integrated in social, family and work spheres. Another factor to consider in post transplant patients is the concept of post traumatic growth, which has been found in post bone marrow transplant patients who report greater appreciation of life and changed priorities (Widows, Jacobsen, Booth-Jones & Fields 2005)

A meta-analysis of 58 relevant studies conducted in Stanford University by Bravata, Olkin, Barnato, Keeffe & Owens (1999) asserted a number of common trends in terms of quality of life in pre and post-transplant patients. Although a variety of instruments were used including both generic and disease specific measurements, all studies reported pre-transplantation impairments. In general, of the 3576 patients incorporated, HRQoL was consistently impaired pre-transplantation and improved post-transplantation. The elements of QoL most affected by physical health showed the greatest improvements. The smaller improvements in psychosocial functioning they concluded were due to the realities of life with a transplant organ, such as immunosuppressant medication, dependence on the

healthcare system and potential discrimination in the workplace.

Tome, Wells, Said and Lucey, (2008) reviewed four longitudinal and sixteen cross-sectional studies which all used The Medical Outcomes 36-Item Short Form Health Survey (SF-36) to compare liver transplant recipients with the general population. They stated that, although longitudinal studies show a great improvement in transplant recipients, cross-sectional analysis shows that considerable deficits remain when compared to the general population.

Assessing HRQoL can also be useful in predicting outcomes such as survival and compliance. Kanwal et al (2009) used a disease specific QoL tool in patients with cirrhosis on the transplant waiting list. In this study survival was strongly predicted by HRQoL. Higher scores on the Short Form Liver Disease Quality of Life Instrument predicted lower mortality in this patient group. Tanikella et al (2010) also noted that perceived HRQoL in pre transplant patients can predict survival rates. Measuring psychosocial well-being has also been seen to be a good predictor of Compliance to the medical regime and the return to alcohol use post transplantation. (Kelly et al 2006; Harper, Wager & Chacko 2010).

There are a wide variety of methods for assessing quality of life. Qualitative studies can give a more in depth insight into the psychosocial experiences of transplant recipients (e.g. Robertson (1999); Collins and Labott (2007); Bjork and Naden (2008) and Rainer, Thompson and Lambros (2010)) which can be helpful in exploring individual difficulties. However using quantitative analysis, groups of patients can be compared using a standardised method. Changes in perceived HRQoL can also be quantified by assessing patients before and after procedures. The number of different QoL measurements can make generalizing

across studies difficult. Condition specific measures can give a better insight into specific disease related issues. However generic measures allow researchers to compare patients with healthy members of the general public and can also compare patients between conditions. The appropriate choice of HRQoL questionnaire is an important factor in any study (Hyland 2003). Nord et al (2001) argue that The Medical Outcomes 36 Item Short Form Health Survey (SF-36) questionnaire can yield helpful indications of QoL but not measure it. However it remains the most popular instrument for use in liver transplant patients. It appeared in eleven of the thirteen published studies in 2008 (Jay, Butt, Ladner, Skaro & Abecassis, 2009). As it is so frequently used in the transplant population, results between studies can easily be compared. The SF-36 is widely used because it is multidimensional and it is frequently recommended as the generic core in disease-specific batteries (Bowling 2001 pp 298). It also includes all of the dimensions recommended by Fitzpatrick et al (1992) for generic measurement of quality of life: Physical function, emotional function, social function, role performance, pain and energy/fatigue. The current study uses the SF-36 due to its multifactor approach and also its comparability with other studies. Published norms are also available for comparison (Jenkinson, Coulter & Wright, 1993). These norms indicate that HRQoL is dependent on age and reported medical conditions.

As with all research techniques Quality of Life research produces a number of issues for the researcher. For example Face-to-face data collection may result in an under-reporting of issues on the emotional and mental health scales on the SF36 (Lyons et al., 1999). Another factor to consider is the Saviour Effect, which has been seen in Quality of Life Research. Joralemon & Fujinaga (1996) discussed this phenomenon whereby patients who feel that their lives have been saved by the medical team may under-report impairments in quality of life, as they feel indebted towards the hospital or clinic.

1.4 Perceived Stress in Liver transplant patients

According to Taylor 2009 pp147, Stress is

“A negative emotional experience accompanied by predictable biochemical, physiological, cognitive and behavioral changes that are directed either toward altering the stressful event or accommodating its effects”

To briefly summarise the physical reaction to stress; when exposed to a stressor, the nervous system is activated and a string of biochemical reactions occur. The adrenal glands are stimulated by the hypothalamus to produce more adrenaline and cortisol and these are released into the bloodstream. This causes an increase in heart rate, breathing, blood pressure and metabolism. This stress response should allow the body to deal more effectively with the stressor; however prolonged stress responses can negatively affect health. Good over-all health increases resistance to stress as it improves the capacity for responding to demand according to Rice (1999 pp 395). However chronically ill patients are particularly vulnerable to stress as their health is already compromised. It is important to monitor stress levels in liver patients, as there is evidence which suggests that biochemical reactions to psychosocial stress such as the production of the stress-induced hormones catecholamines can exacerbate liver disease (Chida, Sudo & Kubo 2006). Stress induced Glucocorticoids can also facilitate inflammatory responses in the liver (Vere, Streba, Streba, Ionescu & Sima 2009).

Patients and families often identify the wait for a donor organ as the most psychologically stressful part of the transplant experience (Dew et al 2002). Exposure to high levels of stress is expected in this population. There are many sources stress involved. Frequent hospitalisation, isolation from family and friends, adapting to the patient role and anxiety surrounding the wait for a donor organ are just some of the stressors that can be experienced. Gubby (1998) found that concern about graft rejection and the possibility of

repeated hospitalisations ranked as being particularly stressful to patients. Streisand, et al. (1999) stated that the pre transplant period is highly stressful because of declining health, uncertainty and inability to continue working and participate in daily activities. While attending the clinic patients come to know one another. The death of fellow patients can cause stress but also seeing other patients receive donor organs before them can cause frustration according to Levenson & Olbrisch (1993). The stigma attached to liver transplantation may also be a significant source of stress. Ubel et al (2001) interviewed members of the public and the results showed that people would prefer to allocate organs to those who were not seen to have caused their illness, for example through alcohol or drug use.

The research on stress post transplantation shows no clear picture. A broad improvement in social interaction and overall psychological wellbeing was seen in post liver transplant patients by Tarter et al (1988). They also found that the severity of stress experienced by the patient correlated significantly with the rate of recovery.

Moore, Burrows & Hardy (1997) discussed that after Liver Transplantation, fatigue and confusion are reduced and physical wellbeing, appetite and energy levels are improved. Many threats to wellbeing are overcome and as a result anxiety and depression are significantly lower. However, they also stated that a variety of psychological problems may occur such as, sexual disorders, fantasies about the donor and dissatisfaction with body image. The current study will focus on perceived stress in liver transplant candidates and recipients and will address the lack of research in stress post liver transplantation.

1.5 The use of Coping Strategies in liver transplant patients

The use of various coping strategies has been associated with both Health Related Quality of Life and levels of Stress. Folkman and Moskowitz, (2004) have defined coping as the thoughts and behaviours used to manage the internal and external demands of situations that are appraised as stressful. Various coping strategies used by chronically ill patients can be associated with better psychological adjustment. Theorists have asserted that individuals cope with stressors differently (e.g. Lazarus & Folkman 1980; Carver, Scheier & Weintraub 1989). The contextual approach to coping put forward by Lazarus and Folkman (1984) states that coping processes are not inherently good or bad. This approach evaluates the adaptive qualities of coping in the specific context in which they occur. For example, a coping strategy may be considered adaptive in one situation, but maladaptive in another. They also state that the context is dynamic, so that what might be considered an effective coping strategy when the stressor is first encountered may become ineffective later on.

Traditionally, coping strategies have been grouped into three categories, Emotion-focused coping, Problem-focused coping and Appraisal-focused coping (Ogden 2000 p60). Appraisal focused coping in illness involves attempting to understand the illness. Problem-focused coping involves confronting the problem and attempting to manage it. Emotion-focused coping involves managing emotions and changing the way an individual thinks about the situation. Other styles of coping can include approach coping, which involves doing something actively to help the problem, and avoidant coping, such as denial and distraction where the individual attempts to distance themselves from the problem (Ogden 2000, p49)

Carver, Scheier, and Weintraub (1989) list coping strategies as: active coping, planning, seeking instrumental social support, seeking emotional social support, suppression

of competing activities, turning to religion, positive reinterpretation and growth, restraint coping, acceptance, focusing on and venting emotions, denial, mental disengagement, behavioural disengagement, alcohol/drug use, and humour. In chronically ill patient's an active, confrontive approach to illness, such as information seeking, has been linked to decreased negative effect, whereas wish-fulfilling fantasy and avoidance is linked to poor adjustment (Felton & Revenson 1983). Coping mechanisms in transplant patients change over time and are affected by situational contexts (Forsberg, Backmann & Svensson 2002). It is not possible to define any one coping strategy that works for a given situation, and individual differences can dictate what mechanism is chosen. Having the ability to use the most effective strategy for the given situation and the ability to be flexible in one's coping response is the best strategy according to Cheng (2003). Factors that play important roles in determining an individual's coping response are their appraisal of the situation (Lazarus and Folkman 1984), Levels of optimism, (Chang 1998) self-efficacy, (Bandura 1977) and control. (Folkman 1984).

Karademas, Karamvakalis & Zarogiannos, (2009) found that there was a strong association between life stress and certain coping strategies in patients with chronic illness. They found that higher stress levels were associated with more soothing strategies aimed at reducing discomfort. They also found that higher levels of stress were associated with more negative emotions. Telles-Correia, Barbosa, Mega & Monteiro (2009) assessed 131 liver transplant patients and found that active coping correlated with the physical and mental components of Health Related Quality of life more so than clinical or socio-demographic factors. Kraus, Schafer, Csef, Scheurlen & Faller (2000) also found that active coping styles like problem solving are predominantly used in patients with Chronic Hepatitis C. A negative correlation between the use of non-active strategies and Quality of Life has been found by

Jurado et al (2011). They compared alcoholic and non-alcoholic patients and found no difference regarding the use of coping strategies. This suggests that coping strategies are more dependent on individual factors than disease aetiology.

Levenson & Olbrisch (1993) determined that Avoidance coping can cause a decline in physical and psychological status in transplant patients. Stille et al (2011) have also discovered a significant relationship between coping style and transplant related stress. Nickel, Wunsch, Egle, Lohse and Otto (2002) noted that coping, anxiety and depression, in addition to social factors determine overall wellbeing and health related quality of life after liver transplantation. Meichenbaum and Turk, (1982) suggested that in order to effectively deal with stress, individuals should discover what works best for them. Gutteling, de Man, Busschbach and Darlington (2007) commented that there is a relationship between depression and the psychological variables of coping and self-efficacy. Therefore patients awaiting liver transplantation with impaired health related quality of life should be referred to psychological counselling that focuses on teaching these psychological constructs. Goetzmann et al (2006b) have also highlighted the importance of counselling for patients on the liver transplant waiting list.

1.6 Geographic Proximity and demographic variables

Interesting findings have also come from analysis which includes a number of demographic variables. Hellgren et al (1998) found that liver transplant recipients with a higher degree of education as well as those who are married or cohabitant are better able to manage stressful situations. Female gender was the most important factor contributing to the mental health aspect of HRQoL in a study by Afendy et al (2009). Women in this study reported lower levels of quality of life than male participants. Variables pertaining to employment and

income were also seen to affect HRQoL with individuals who are actively employed showing higher levels of Quality of Life. (Saab et al 2008)


Olbrisch, Benedict, Ashe & Levenson (2002) have noted that living a far distance from the care centre can cause stressors such as difficulty with work and family commitments. Less availability of social support means that these patients will also have fewer visitors during hospital stays. Patients who live outside the transplant centre area must be able to get to the hospital quickly as the organ must be transplanted in a relatively short time. This may mean that they have the burden of relocating temporarily (Engle 2001). In a study of Irish transplant patients, McCormick, O'Rourke, Carey and Laffoy (2004) found that Irish patients living far from the centre may be at a disadvantage when it comes to allocation of resources and receiving a liver transplant. Axelrod et al (2008) also found that Patients living in rural areas had a lower rate of wait-listing and transplant of solid organs. According to Molinari, Renfrew, Petrie, De Coutere and Adbolell, (2010) patients on the liver transplant waiting list living in rural areas have a significantly higher mortality rate. This finding was independent of disease severity. They concluded that this may be due to less access to specialized care. While there is evidence which suggests geographic proximity can affect medical outcomes, Quality of Life has not yet been considered as a factor

Firozvi, Lee and Hayashi, (2008) looked at travel time for liver transplant patients with reference to health outcomes, comparing patients with greater than 3 hours travel time to patients with less than 3 hours travel time. This study used Yahoo! Maps to calculate the distance by car from the patient's area of residence to the transplant centre. While they concluded that longer travel times between the home and the transplant centre does not have an effect on clinical outcomes, they noted that distant patients face higher travel costs and

may be referred to specialist clinics less often. The study did not take quality of life into consideration, but it included a psychosocial evaluation score as a variable. However the method for obtaining this score was by assessment of social worker narrative, where the authors assigned a score of Good, Fair, Marginal and Poor. No significant relationship was found between psychosocial evaluation score and travel time to the transplant centre; however the method of measuring psychosocial well-being was questionable.

1.7 Rationale and Aims

The aim of liver transplantation is no longer purely to prolong survival but also to improve quality of life (Kim 2000). By conducting an assessment on quality of life, the transplant team can not only obtain information about the patient's biological, psychological and social limitations, but it can also establish a baseline to which they can be subsequently measured. This leads to the possibility of addressing any of the limitations or problems which persist following transplantation. (Widows & Rodrigue 2003 p 282).

 Hospital is the specialist centre for liver transplantation in the Republic of Ireland. The catchment area covers the entire country. Due to the large area covered by the hospital and the frequency of visits needed by chronically ill patients, the study aims to investigate how this affects individuals who have to travel far distances to their appointments in terms of their health related quality of life and levels of perceived stress. This can be an important factor for patients as the ease or difficulty of the process of entry into the medical facility can affect illness, adding or removing levels of stress (Shuman 1996 pp 7). The study aims to investigate the effect of transplant status on health related quality of life and perceived stress levels in patients attending the liver transplant clinic. It intends to test previous studies that claim that health related quality of life is greatly improved after

liver transplantation. It is predicted that health related quality of life will be higher in patients in the post-transplant group than in the pre transplant group. Furthermore, it is predicted that perceived stress levels will be higher in the pre transplant group.

The study will also look at the various coping strategies that are used by both pre and post-transplant patients. It will look at the coping strategies used by patients and how they relate to their health related quality of life and levels of perceived stress. Finally along with a number of other demographical data (Gender, Marital Status and Employment Status) this study will investigate whether there are differences in HRQoL and perceived stress when taking geographical proximity to the hospital into consideration. The effect of age will also be controlled for. A number of hypotheses will be tested;

It is hypothesised that:

- (i) Health related quality of life will be significantly higher in the post-transplant group than in those in the pre transplant group.
- (ii) Levels of perceived stress will be significantly increased in the pre transplant group.
- (iii) There will be a significant relationship between the coping strategies used by patients and their health related quality of life and levels of perceived stress.
- (iv) There will be a significant differences in health related quality of life and perceived stress levels depending on a patients area of residence while controlling for the effects of age
- (v) HRQoL and Perceived Stress will be significantly affected by gender, marital status and employment status while controlling for the effects of age.

2.0 Methods

2.1 Materials

The current study used a self-administered, paper-and-pencil questionnaire. All questionnaires were entirely anonymous. The first section of the questionnaire was designed to elicit demographic data only and consisted of questions related to Transplant status, Time since transplant, Age, Gender, Relationship status, Employment status and geographical Province. Time since transplant was only included to assess eligibility for the study and was not included in the analysis.

The Medical Outcomes Study 36-Item Short Form (SF-36) health survey Rand Version 1.0 (Ware & Sherbourne 1993) was employed as a multidimensional indicator of Health Related Quality of Life. The questionnaire comprises 36 questions which represent eight subscales: Physical functioning, (10 items; $\alpha=0.90$) Role limitations due to physical health (4 items; $\alpha=0.88$), Role limitations due to emotional problems (3 items; $\alpha=0.80$), Energy/Fatigue (4 items; $\alpha=0.85$), Mental Health (5 items; $\alpha=0.83$), Social Functioning (2 items; $\alpha=0.76$), Pain (2 items; $\alpha=0.82$) and General Health perceptions (5 items; $\alpha=0.80$). Each subscale indicates good internal consistency reliability and validity (Jenkinson, Coulter & Wright 1993). The formats of the questions vary from section to section, ranging from a Yes or No answer to a 6-point likert scale (See appendix for questionnaire). Questions are scored on a scale from 0 to 100. A score of 100 represents the highest possible functioning and a score of 0 represents the lowest. The scores representing each subscale are averaged to get a score between 0 and 100. A higher score indicates a higher level of functioning for each subscale, for example a higher score in the Pain subscale relates to a higher level of functioning in relation to pain and not a higher level of physical pain.

Perceived stress scale (PSS-10) Questionnaire (Cohen 1983) measures the extent to which life situations and appraised as stressful. It consists of ten questions, which are answered via a five point likert scale. Participants are asked how often they have felt a certain way with answers ranging from “Never” to “Very Often”. Scores are obtained reversing four positive items and then summing across the ten items. Possible scores range from 0-40 with a higher score indicating higher levels of perceived stress. The Perceived Stress scale has good internal consistency reliability ($\alpha = 0.84$) and has good validity.

The Brief COPE Questionnaire (Carver 1997) was used to investigate coping strategies used by patients. It is an abbreviated version of the COPE (Carver, Scheier & Weintraub 1989) consisting of 14 subscales, each containing 2 items: Self-distraction ($\alpha=0.71$), Active coping ($\alpha=0.68$), Denial ($\alpha=0.54$), Use of emotional support ($\alpha=0.71$), Use of instrumental support ($\alpha=0.64$), Behavioural disengagement ($\alpha=0.65$), Venting ($\alpha=0.50$), Positive reframing ($\alpha=0.64$), Planning ($\alpha=0.73$), Humour ($\alpha=0.73$), Acceptance ($\alpha=0.57$), Religion ($\alpha=0.82$) and Self-blame ($\alpha=0.69$). The scale also includes a substance use subscale ($\alpha=0.90$), however substance use is an absolute contraindication to liver transplantation, therefore so as not to compromise any patient on the waiting list the items related to alcohol and substance use were excluded. Questions are answered via a four-point likert scale with responses ranging from “I haven’t been doing this at all” to “I have been doing this a lot”

2.2 Participants

The population studied were patients attending the liver transplant clinic in [REDACTED] Hospital Liver Unit who were either waiting on or had received a liver transplant. A total of sixty (N=60) eligible patients were invited to take part in the study. Forty-eight (N= 48) patients consented to participate, however two participants withdrew before fully completing the

questionnaire. Of the forty-six participants who completed the questionnaire twenty-six (N=26) were post-liver transplantation and twenty (N=20) were on the liver transplant waiting list. Opportunity sampling was employed, with eligible participants selected from the clinic's waiting list. Patients did not benefit directly from their participation.

A number of inclusion and exclusion criteria were put in place to select eligible participants. Individuals considered eligible for participation in the study were those who had received a liver transplant at least six months prior to the beginning of the study and patients who are either on or being assessed for inclusion on the liver transplant waiting list. Individuals excluded from the study were those who were under 18 years of age, those unable to give informed consent and patients suffering from any symptoms of confusion or impaired cognitive functioning. This is not uncommon in transplant patients. Patients who have received a liver transplant for acute liver failure were also excluded. This was to exclude any individuals who have had a transplant due to drug overdose, as these patients do not fit the same model as chronically ill patients. Every effort was made to insure that only patients who fit into the inclusion criteria were invited to participate.

2.3 Design

The study employed a cross-sectional, correlational, questionnaire based design. The analysis was quantitative in nature. Opportunistic sampling was employed. The study took a quasi-experimental approach, comparing two groups of patients. The predictor variables included Coping Strategies (Self-distraction, Active coping, Denial, Use of emotional support, Use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humour, Acceptance, Religion, Self-blame) Transplant Status (pre or post liver transplant) and time since transplant. Demographic variables: (Age, Gender, Employment Status,

Relationship Status, Proximity to Hospital). The criterion variables included Health Related Quality of Life (vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health) and Perceived Stress Levels.

2.4 Procedure

Participants were recruited from the Liver Unit out-patient clinics. Permission to access the clinics was obtained from the two consultant Hepatologists in [REDACTED] Hospital. Suitable participants were invited to complete the questionnaire in the clinic's waiting rooms. A list of eligible participants was compiled before each clinic on the advice of a liver transplant co-ordinator who consulted patient medical records. In accordance with [REDACTED] Hospital guidelines two separate patient information leaflets were designed for pre and post transplant patients. All individuals were advised of their right to refuse to participate or to withdraw from the study before submitting the questionnaire. Participants were given the opportunity to read through the relevant patient information leaflet and questionnaire and were given the opportunity to ask questions before consenting. Both the participant and the investigator signed a consent form (See Appendix for Patient information leaflet and consent form). In order to insure confidentiality questionnaires were returned in sealed anonymous envelopes with the consent forms kept separately from the questionnaires.

2.5 Data Analysis

For the purpose of data analysis scores on the SF-36 were computed using Physical and Mental Component Scores. Physical Component Scores (PCS) consisted of four subscales (Physical functioning, Role Physical, Bodily Pain and General Health). Mental Component

Scores consisted of the remaining four subscales (Vitality, Social Functioning, Role Emotional and Mental Health) (Ware et al 1995).

An independent samples t-test was used to investigate significant differences between pre and post-transplant patients for mean scores on the SF-36. A Pearson's R Correlation was used to establish relationships between coping strategies and the out-come variables of Physical and Mental Component Scores of the SF-36 and Perceived Stress. Finally an analysis of covariance (ANCOVA) was used to investigate significant differences in the demographic variables of gender, employment status, marital status and Area of Residence (Province), on scores on the SF-36 and Perceived stress scale, with age entered as a co-variant.

2.6 Ethical Considerations

The [REDACTED] Ethics and Medical Research Committee reviewed and approved the current study including all relevant documentation (See Appendix for completed ethics form submitted to [REDACTED] Hospital Ethics Committee). The study was also reviewed and approved by the Dublin Business School Ethics Committee.

(ethics forms removed to preserve patient anonymity)

3.0 Results

Descriptive Statistics

A total of 46 participants were included in the current study. Twenty six (N=26) were post transplantation and twenty (N=20) were on the liver transplant waiting list. The gender breakdown was 56.5% Male (N=26) and 43.5% female (N=20). The majority of participants in the study were married (58.7%, N=27). 17.4% (N=8) patients were single, 8.7% (N=4) were in a relationship, 13% (N=6) were divorced or separated and one participant (N=1, 2.2%) was widowed.

The majority of participants in this sample were unemployed (58.1%, N=25), with only 18% (N=8) being employed full-time. Three participants (N=3, 7%) were employed part time, Two, (N=2, 4.7%) were students and 11.6% (N=5) participants were retired. In terms of Area of Residence, 48.8% (N=21) of the patients lived within Leinster, 25.6% (N=11) lived in Munster, 16.3% (N=8) lived in Connaught and 9.3% (N=4) lived in Ulster. 58.7% (N=27) participants described their area of residence as Urban and 41.3% (N=19) reported living in a Rural area.

Table 1.0 represents mean and standard deviations for pre and post-transplant patient's scores for the SF-36 and perceived stress questionnaires including published norms for each. Post-transplant patients scored higher in all subscales of the SF-36 and lower on the perceived stress scale than pre transplant patients. Both groups scored lower than published norms on all subscales of the SF-36 except for vitality where post-transplant patients scored higher. Both groups reported higher levels of perceived stress than published norms.

Table 1.0 *Mean and standard deviation for pre and post-transplant patients on SF-36 and Perceived Stress Scales including published norms for each.*

	Pre transplant	Post transplant	Published Norms ^{1,2}
	M(SD)	M(SD)	M(SD)
Physical functioning	14.75 (28.29)	84.80 (15.52)	92.5(13.4)
Social Functioning	12.50 (25.00)	88.46 (23.69)	91.3(15.8)
Physical Role limitations	41.66 (41.71)	78.20 (33.92)	91.4(23.2)
Emotional Role limitations	37.25 (19.77)	69.61 (21.26)	85.6(29.3)
Mental Health	47.40 (18.36)	73.38 (16.78)	75.4(16.3)
Vitality	35.00 (29.13)	83.65 (19.61)	64.0(18.2)
Pain	46.75 (29.81)	84.23 (21.51)	86.3(17.9)
General Health	22.50 (15.69)	61.20 (20.93)	78.8(15.7)
Perceived Stress	21.10 (2.77)	20.07 (2.53)	13.02(6.35)

¹Published norms for SF-36, (Jenkinson, Coulter & Wright 1993)

²Published norms for PSS-10 (Cohen 1983)

Inferential Statistics

An independent samples t-test found that there was a significant difference between pre and post-transplant patients in all subscales of the SF-36. Post-transplant patients scored significantly higher in all domains (See table 2.0)

Table 2.0 SF-36 mean scores for pre and post-transplant patients

Variable	Pre-transplant (n=20) M (SD)	Post-transplant (n=26) M (SD)	t(df)	P value
Physical Functioning	14.75 (28.29)	84.80 (15.52)	t(27.69) = 6.589	0.000
Role Limitations due to Physical Health	12.50 (25.00)	88.46 (23.69)	t(39.87) = 10.449	0.000
Role limitations due to emotional problems	41.66 (41.71)	78.20 (33.92)	t(36.14) = 3.190	0.003
Vitality	37.25 (19.77)	69.61 (21.26)	t(42.36) = 5.327	0.000
Mental Health	47.40 (18.36)	73.38 (16.78)	t(39.01) = 4.938	0.000
Social Functioning	35.00 (29.13)	83.65 (19.61)	t(44) = 6.763	0.000
Pain	46.75 (29.81)	84.23 (21.51)	t(33.22) = 4.751	0.000
General Health Perceptions	22.50 (15.69)	61.20 (20.93)	t(42.85) = 7.086	0.000

As illustrated in the above table significant differences were found between pre and post transplant patients for physical functioning ($t(27.69) = 6.32$, $p < 0.001$, eta squared 0.50); Role limitations due to physical health ($t(39.87) = 10.449$, $p < 0.001$, eta squared 0.71); Role limitations due to emotional problems ($t(36.14) = 3.190$, $p < 0.01$, eta squared 0.18); Vitality ($t(42.36) = 5.327$, $p < 0.001$, eta squared 0.39); Mental Health ($t(39.01) = 4.938$, $p < 0.001$, eta squared 0.36); Social Functioning ($t(44) = 6.763$, $p < 0.001$, eta squared 0.51); Pain ($t(32.22) = 4.751$, $p < 0.001$, eta squared 0.34) and General Health Perceptions ($t(42.85) = 7.086$,

$p < 0.001$, eta squared 0.53). Eta squared values indicate a large effect size for all domains.

Correlations

A Pearson's R correlation was employed to investigate relationships between coping strategies and Physical and Mental Component scores of SF-36 and Perceived stress scale. A summary of significant relationships is illustrated in table 3.0 below. There was a significant strong negative relationship between Self-Blame and the physical component of Quality of life ($r = -.50$, $p = .001$, 2-tailed). This indicates that the more Self-Blame was used the lower the Physical component Score. There was a significant moderately strong negative relationship between Acceptance and physical component score ($r = -.45$, $p = .002$, 2-tailed). This indicates that the more the acceptance coping strategy was used the lower the physical component score. A significant moderately strong negative relationship was found between Humour and Physical Component Score ($r = -.45$, $p = .002$, 2-tailed). This indicates that the more the Humour coping strategy was used the lower the physical component score. A significant moderately strong relationship negative was found between Religion and Physical component score ($r = -.43$, $p = .003$, 2-tailed). This indicates that the more the Religion coping strategy was used the lower the physical component score.

There was a significant moderately strong negative relationship between Self Blame and Mental Component Score on SF-36 ($r = -.44$, $p = .002$, 2-tailed). This indicates that the more Self-Blame was used the lower the Mental Component Score. There was a significant moderately strong negative relationship between Acceptance and Mental Component Score ($r = -.41$, $p = .005$, 2-tailed). This indicates that the more acceptance was used the lower the mental component score. A significant moderately strong negative relationship was found between Humour and Mental component score ($r = -.38$, $p = .010$, 2-tailed). This indicates that

the more Humour was used the lower the Mental Component Score. There was a significant moderately strong negative relationship between denial and Mental Component Score ($r = -.36$, $p = .016$, 2-tailed). This indicates that the more Denial was used the lower the Mental Component Score. There was a significant moderately strong negative relationship between Planning and Mental Component Score ($r = -.29$, $p = .047$, 2-tailed). This indicates that the more planning was used the worse the mental component score.

No significant relationships were found between any of the coping strategies with levels of perceived stress.

Table 3.0 Correlations for Coping Strategies with Physical and Mental Component Scores of SF-36 Showing Significant Relationships only.

	Physical Component Score	Mental Component Score
Self- Blame	-.497**	-.436**
Acceptance	-.451**	-.408**
Humour	-.453**	-.377**
Religion	-.431**	
Denial		-.358*
Self-Distraction		-.300*
Planning		-.294*

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

One way between groups analyses of covariance (ANCOVA) were conducted to investigate differences in the outcome variables of SF-36 component scores and Perceived stress for transplant status, gender, marital status, employment status and area of residence (province). Age was entered as a covariate as age has been shown to have an effect on quality of life. After adjusting for age, only transplant status was seen to have a significant main effect on the mental health component of HRQoL ($F(1,26) = 21.72$, $p < 0.001$). There were no significant differences found for Gender ($F(1,26) = 0.18$, $p > 0.05$); Marital Status ($F(4,26) = 0.44$, $p > 0.05$);

Employment Status ($F(4,26)=1.02, p>0.05$) or Province ($F(3,26)=1.35, p>0.05$).

After adjusting for age, only transplant status was seen to have a significant main effect on the physical health component of HRQoL ($F(1,26)=112.41, p<0.001$). There were no significant differences found for Gender ($F(1,26)=1.37, p>0.05$); Marital Status ($F(4,26)=1.33, p>0.05$); Employment Status ($F(4,26)=1.69, p>0.05$) or Province ($F(3,26)=1.47, p>0.05$).

There were no significant differences found for Perceived Stress and Transplant status ($F(1,26)=2.92, p>0.05$). Gender ($F(1,26)=0.46, p>0.05$); Marital Status ($F(4,26)=0.65, p>0.05$); Employment Status ($F(4,26)=0.68, p>0.05$) or Province ($F(3,26)=1.11, p>0.05$). Age was not found to be significant in any of the analyses.

4.0 Discussion

The present study aimed to investigate the effect of transplant status on health related quality of life and perceived stress levels in patients attending the liver transplant clinic in ██████████ Hospital. It also investigated the various coping strategies used by patients and how they relate to their health related quality of life and levels of perceived stress. Finally along with a number of other demographical data this study investigated whether there is a relationship between geographical proximity to the hospital and Health Related Quality of Life and perceived stress in these patients

The first aim of the current study was to investigate if patients who have received a liver transplant have better health related quality of life than patients who were on the liver transplant waiting list. Consistent with previous literature, the study found that the post liver transplant patients have a significantly higher level of quality of life in all domains as measured by the SF-36 questionnaire. Physical, Social and Psychological variables were incorporated and the post transplant patients scored higher in all subscales, thus indicating that receiving a liver transplant has a large effect on health related quality of life in this patient population. The current research supports previous studies that have concluded that liver transplant patients have an improved level of HRQoL after receiving a transplant organ (Kober et al 1990; Hicks, Larson & Ferrans 1992; Moore et al 1992; DeBona et al 2000; Moore, Jones & Burrows 2000). The results are also in keeping with the Meta-analysis carried out by Bravata et al (1999).

The second aim of the study was to investigate whether pre liver transplant patients had higher levels of perceived stress than post liver transplant patients. It was hypothesised that pre transplant patients would have increased levels of perceived stress, when compared

to post transplant patients. While there was no significant difference found between the two groups, mean scores for both pre and post transplant patients were higher than published norms. High levels of perceived stress were expected in the pre-transplant group due to stressors such as frequent hospitalisation, isolation from family and friends, adapting to the patient role and anxiety surrounding the wait for a donor organ (Gubby 1998) and also declining health, uncertainty and inability to continue working and participate in daily activities (Streisand et al, 1999). However the high scores in the post transplant group would suggest that even after receiving a liver transplant, levels of stress remain high. High levels of stress in post transplant patients could be explained by the realities of life with a transplant organ, such as immunosuppressant medication, dependence on the healthcare system and potential discrimination in the workplace (Bravata et al 1999). Other considerations include sexual disorders, fantasies about the donor and dissatisfaction with body image (Moore, Burrows & Hardy 1997).

The study also aimed to determine if individual coping strategies were related to Health related Quality of Life and levels of Perceived stress. Consistent with previous research, coping strategies were found to be related to overall well being in liver transplant patients (Nickel et al 2002; Stilley et al 2011). The use of non-active coping strategies have also been seen to be negatively correlated with Quality of Life (Jurado et al 2011). The results of the current study shows a number of negative correlations between coping strategies and both physical and mental aspects of quality of life.

The use of Humour, Acceptance and Self-Blame were found to be negatively related to both Physical and Mental Domains of HRQoL. Each of these coping strategies can be described as emotion-focused coping strategies as they are involved in changing the way an

individual feels about a situation. This suggests that the more these emotion-focused coping strategies are used the lower the overall quality of life in the patient. Self-Blame was most strongly correlated with physical aspects of HRQoL which would suggest that the more a patient blames themselves for their illness, the lower their physical well-being. In terms of Physical Components of Quality of life, lower levels of physical health were related to more use of Self-Blame, Acceptance, Humour and Religion as coping Strategies. Turning to Religion was negatively related to the Physical Health aspect of Quality of Life but not significantly related to the Mental Health aspect. This finding could suggest that as a patient's physical health declines they are more likely they are to turn to Religion in an attempt to cope with their illness.

More Coping strategies were found to be related to the mental health components of HRQoL. There were negative relationships found between mental well-being and the use of Self-Blame, Acceptance, Humour, Self-Distraction, Denial and Planning. Self-Distraction and denial have been described as avoidant coping styles. Avoidant styles of coping, such as self-distraction and denial, have previously been seen to be related to a decline in physical and psychological status in transplant patients (Levenson & Olbrisch 1993). Planning has often been described as an active coping strategy however it was seen to have a negative relationship with mental health. This would support Lazarus & Folkman's (1984) theory that one coping strategy is not necessarily good or bad, but that it depends on the situation and the outcome that follows its use. The finding that psychological constructs of coping strategies are significantly related to physical health supports the concept of a biopsychosocial approach to health care, showing that biological, psychological and social factors can interact with each other.

There were no significant relationships found between individual coping strategies and levels of perceived stress, with stress remaining high in the population. This combined with the predominately negative relationships between coping and HRQoL, would suggest that the patients in this population are not using effective coping strategies.

The next aim of the study was to investigate whether a patient's proximity to the hospital had an effect on their HRQoL and Levels of perceived stress. Proximity to a healthcare facility has previously been shown to affect patient's physical health, access to treatment, and mortality rate (McCormick et al 2004; Axelrod et al 2008; Molinari et al 2010) However Quality of life has not previously been considered. For this patients were assessed based on the geographical Province that they live in. No significant difference was found for quality of life or stress in terms of a patient's area of residence. It is possible however that this outcome was affected by the small sample size in the study. A larger, more representative sample may produce different results.

Similarly, no significant differences were seen for any of the demographic variables age, gender, marital status or employment status. These findings were contrary to previous research that found that women had lower levels of emotional well-being (Afendy et al 2009). They were also in contrast with the finding that employment status can have an effect on Quality of Life (Saab et al 2008). It is important to note here however that the rate on unemployment in this population was 58.1%, with only eight of the forty-six participants being employed full-time. It is possible that the sample size was not sufficiently large to find any significant differences for the number of variables tested and therefore further research with a larger sample would be useful.

An additional finding of the present study is that when comparing HRQoL scores of participants to normative data, post-transplant patients scored higher on vitality than individuals who did not report having a long standing illness (Jenkinson, Coulter & Wright 1993). A similar finding was discussed by Beilby, Moss-Morris and Painter (2003) who suggested that it could be explained by a contrast effect, whereby transplant recipients are likely to perceive their quality of life as higher due to the contrast between their pre and post transplant functioning.

4.1 Limitations

As with all research, a number of limitations have been acknowledged in the current study. It is therefore important to be tentative in interpreting these results. Firstly, the sample size in this study (N=46) is small. While the number of participants reflects the short period of time available for data collection and the specialised nature of the study, a larger number of participants would give more strength to the findings.

Secondly during the data collection stage, a small number of the participants verbally reported having a co-occurring condition that was unrelated to their liver condition. This information was not formally recorded on the questionnaire but was noted for discussion. A large number of demographic factors were investigated, however the study did not control for the possibility that a number of the participants in the study may have be suffering from a co-existing medical condition, which may also have an effect on their quality of life. It is therefore difficult to ascertain how much of the impairment in quality of life was as a result of unrelated co-occurring conditions.

Finally, this research was carried out in the outpatient clinic of the liver unit in [REDACTED] [REDACTED] Hospital, where the participants are currently being treated. It is therefore important to consider the Saviour Effect, whereby post-transplant patients may have under-reported QoL impairments due to a feeling of indebtedness towards the clinic (Joralemon & Fujinaga 1996).

4.2 Recommendations

Although the current study has shown that Health Related Quality of Life is significantly higher in post transplant patients than in pre transplant patients, more research is needed. A cross-sectional design was employed due to time restrictions; however a longitudinal study would provide a greater insight into individual changes in QoL across the transplantation process. In addition, a qualitative element would be beneficial in understanding individual attitudes and challenges. A larger sample size would be desirable in future research as the sample in the current study may not have been sufficiently representative for the number of demographic variables investigated.

The additional finding of this study and of Beilby, Moss-Morris and Painter (2003), that post transplant patients report higher levels of vitality than normative data, could be an important area for further study. The higher levels of vitality may be explained by a contrast effect as indicated, however another avenue for investigation could be post traumatic growth. Patients who have been terminally ill on the transplant list may experience post-traumatic growth after receiving the life saving organ transplant. This has previously been found in patients who have received bone marrow transplants (Widows, Jacobson, Booth-Jones & Fields 2005).

The study found that perceived stress levels remained high in post transplant patients. This would suggest that these patients need continued care after transplantation and help in dealing with various stressors such as the use of immunosuppressant drugs, lifestyle changes and dependence on the healthcare system. Therefore continued psychological care after the transplantation process is recommended. The relationship between coping strategies and HRQoL found in the current study would indicate that counselling that teaches patients more effective coping strategies would be beneficial (Goetzmann et al (2006b); Gutteling et al (2007)). Coping strategies that are maladaptive may be an important target of psychological intervention for transplant patients according to Widows & Rodrique (2003, p 287). Self-Blame was found to have the strongest relationship with Health related Quality of Life. The more self-blame was used, the lower the levels of physical and emotional well-being. This finding would suggest that helping patients to overcome issues and stop blaming themselves for their illness could be beneficial and help to enhance their over all quality of life.

Currently the Liver Unit in [REDACTED] Hospital has no standardised procedures for assessing HRQoL in patients before and after liver transplantation. To date there have been no published studies investigating the psychosocial well-being of liver transplant patients in Ireland. The biological, social and psychological problems of liver transplant patients in Ireland should be addressed and the possible actions to facilitate these patients should be examined. This is especially important as rates of alcoholic liver disease in Ireland are increasing (Mongan et al 2011) and the need for liver transplantation may increase accordingly. While efforts should be made to prevent this, it is also important to be prepared for its occurrence. Improved knowledge of psychosocial issues facing liver transplant patients may also help predict compliance and return to alcohol use post-transplantation (Kelly et al 2006;Harper, Wager & Chacko 2010).

It is hoped that from this research, there will be increased awareness of the psychosocial problems experienced by patients before and after receiving a liver transplant. Increased understanding in Healthcare professionals may allow them to better cater for these patients. Increased knowledge of effective coping strategies may reduce stress levels and improve Quality of Life. This may in turn improve success rates in treating the disease. Furthermore it is envisaged that this study may inspire further research that will result in standardized assessment and care that focuses on the biological, psychological and social aspects of chronic and end stage liver disease and liver transplantation.

4.3 Conclusion

The present study found that liver transplant recipients report higher levels of Health related Quality of Life than patients on the transplant list. Levels of perceived stress were high in both pre and post transplant groups. The use of more emotion focused coping strategies were negatively related to physical components of Health Related Quality of life. The predominately negative relationships between coping strategies used and Health Related Quality of life, combined with the high levels of stress reported, would indicate that the patients in this population are not using effective coping strategies to deal with the stressors and impairments in Quality of Life involved in the transplantation process. No previous published studies have been found in the Irish populations of liver transplant patients and therefore this study contributes to research as an Irish perspective. Further research in this population is required using a larger sample and a longitudinal approach would be desired. Finally, the finding that psychological constructs of coping strategies are significantly related to both physical and mental health, including social functioning, supports the concept of a biopsychosocial approach to health care, showing that biological, psychological and social

factors can interact with each other. The findings of this study suggest that receiving a liver transplant may improve quality of life, however continued psychological care is recommended as well as teaching patients effective coping strategies to use before and after the procedure.

References

- Afendy A, Kallman J.B, Stepanova M, Zounoszai Z, Aquino R.D, Bianchi G, Marcgesini G, Younossi ZM, (2009) Predictors of health-related quality of life in patients with chronic liver disease. *Alimentary Pharmacology & Therapeutics* Vol 30, 469-476
DOI:10.1111/j.1365-2036.2009.04061.x
- Axelrod D.A, Guidinger M.K, Finlayson S, Schaubel D.E, Goodman D.C, Chobanian M, Merion R.M, (2008) Rates of Solid-Organ Wait-listing, Transplantation, and Survival Among Residents of Rural and Urban Areas. *JAMA*, January 9/16, 2008—Vol 299, No. 2
- Bandura, A., (1977) Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, Vol 84(2), Mar 1977, 191-215. doi:10.1037/0033-295X.84.2.191
- Beilby S, Moss-Morris R & Painter L, (2003) Quality of life before and after heart, lung and liver transplantation. *The New Zealand Medical Journal* Vol 116 No 1171. Retrieved from URL:<http://www.nzma.org.nz/journal/116-1171/318/>
- Bean K.B & Wagner K (2006) Self-Transcendence, Illness Distress and Quality of Life Among Liver Transplant Recipients. *The Journal of Theory Construction and Testing* Vol 10 No 2

Bishop M (2005) Quality of Life and Psychosocial Adaptation to Chronic Illness and Acquired Disability: A Conceptual and Theoretical Synthesis. *Journal of Rehabilitation Vol 71 No 2 5-13*

Bjork I.T & Naden D, (2008) Patients' experiences of waiting for a liver transplantation. *Nursing Inquiry 15(4) 289-298*

Blackburn P, Freeston M, Baker CR, Jones DEJ, Newton JL, (2007) The role of psychological factors in the fatigue of primary biliary cirrhosis. *Liver International DOI; 10.1111/j.1478-3231.2007.01500.x*

Bowling A, (2001) *Measuring Disease: A review of disease-specific quality of life measurement scales (second edition)* Open University Press

Bravata D.M, Olkin I, Barnato A.E, Keeffe E.B & Owens D.K (1999) Health-Related Quality of Life After Liver Transplantation: A Meta-Analysis. Technical Report: No. 1999-2. Retrieved from URL:<http://www-stat.stanford.edu>.

Carver C.S, Scheier M.F, Weintraub J.K, (1989) Assessing Coping Strategies: Theoretically Based Approach. *Journal of Personality and Social Psychology Vol 56 No 2;267-283*

Carver C.S, (1997) You want to Measure Coping But Your Protocol's Too Long: Consider the Brief COPE, *International Journal of Behavioural Medicine, Vol 4 No 1;92 100*

- Chang E.C, (1998) Dispositional Optimism and Primary and Secondary Appraisal of a Stressor: Controlling for Confounding Influences and Relations to Coping and Psychological and Physical Adjustment *Journal of Personality and Social Psychology* 1998, *V>1. 74, No. 4, 1109-1120* doi: 10.1037/0022-3514.74.4.11)9
- Cheng, C. (2003). Cognitive and motivational process underlying coping flexibility: A dual-process model. *Journal of Personality and Social Psychology*, 84, 425-438. doi: 10.1037/0022-3514.84.2.425
- Chida Y, Sudo N & Kubo C (2006) Does stress exacerbate liver disease? *Journal of Gastroenterology and Hepatology Vol 21 No 1* DOI: 10.1111/j.1440-1746.2006.04110.x
- Cohen S, Kamarak T, Mermelstein R, A Global Measure of Perceived Stress (1983) *Journal of Health and Social Behaviour Vol 24* 385-396
- Collins C.A & Labott S.M (2007) Psychological Assessment of Candidates for Solid Organ Transplantation. *Professional Psychology: Research and Practice. Vol 38 No 2, 150-157* DOI:10.1037/0735-7028.38.2.150
- De Bona M, Ponton P, Ermani M, Iemmolo RM, Feltrin A, Boccagni P, Gerunda G, Naccarato R, Rupolo G, Burra P. (2000) The impact of liver disease and medical complications on quality of life and psychological distress before and after liver transplantation. *Journal of Hepatology, Vol. 33, Issue 4, p609-15, - 593p*

- Dogar IA, Siddiqui N, Bajwa A, Bhatti A, Haider N, Hashmi ZY (2009) Relationship between liver diseases and levels of anxiety and depression. *Journal of Pakistan Psychiatric Society* 6(2): 61-64
- Engle G.L, (1997), The Need for a New Health Model: A challenge for Biomedicine. *Science*, Vol 196, Number 4286. Retrieved from <http://faculty.weber.edu> 02/02/12
- Engel G.L, (1980) The clinical application of the bio psychosocial model. *American Journal of Psychiatry*
- Engle D (2001) Psychosocial Aspects of the Organ Transplant Experience: What Has Been Established and What We Need for the Future. *Journal of Clinical Psychology*. Vol 57(4) 521-549
- Fayers P & Bjordal K, (2001) Should Quality of Life needs influence resource allocation? *The Lancet* Vol 357
- Felton BJ, Revenson TA (1984) Coping with Chronic Illness: A Study of Illness Controllability and the Influence of Coping Strategies on Psychological Adjustment. *Journal of Consulting and Clinical Psychology* Vol 52, No 3, 343-353
- Firozvi A.A, Lee C.H, Hayashi P.H (2008) Greater Travel Time to a Liver Transplant Center Does Not adversely Affect Clinical Outcomes. *Liver Transplantation* Vol 14:18-24 DOI 10.1002/lt.21279

Fitzpatrick R, Fletcher A, Gore S, Jones D, Spiegelhalter D, Cox D (1992) Quality of life measures in health care I: Applications and Issues in assessment. *British Medical Journal* 305:1074-7

Folkman S, (1984) Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology*, Vol 64(4) doi:10.1037/0022-3514.46.4.839

Folkman, S., & Moskowitz, J.T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774. DOI: 10.1146/annurev.psych.55.090902.141456

Forsberg A, Lorenzon U, Nilsson F, Backman L, (1999) Pain and Health Related Quality of Life after heart, kidney, and liver transplantation. *Clinical Transplantation* vol13 No 6 453-460 DOI: 10.1034/j.1399-0012.1999.130603.x

Forsberg A, Backman L, Mollers A. (2000) Experiencing liver transplantation: a phenomenological approach. *Journal of Advanced Nursing* 32(2) 327-334

Forsberg A, Backman L, Svensson E (2002) Liver transplant recipients' ability to cope during the first 12 months after transplantation - a prospective study. *Scandinavian Journal of Caring Sciences* 16; 345-352

Goetzmann L, Klaghofer R, Wagner-Huber R, Halter J, Boehler A, Muellhaup B, Schanz UBuddeberg C, (2003) Quality of life and psychosocial situation before and after a lung, liver or an allogeneic bone marrow transplant. *Swiss Medical Weekly* ; 136 : 281 – 290 Retrieved from www.smw.ch

Goetzmann L, Wagner-Huber R, Klaghofer, R, Muellhaupt, B, Clavien P, Buddeberg C, Scheuer E (2006), Waiting for a liver transplant, Psychosocial well-being, Spirituality and need for Counselling. *Transplantation Proceedings, Vol 38, Issue 9, 2931-2936* [dx.doi.org/10.1016/j.transproceed.2006.08.171](https://doi.org/10.1016/j.transproceed.2006.08.171),

Gubby L, (1998) Assessment of quality of life and related stressors following liver transplantation. *Journal of Transplant Co-ordination, Vol 8 No 2 8:113-118*

Gutteling JJ, de Man RA, Busschbach JV, Darlington AE (2007) Health related quality of life and psychological correlates in patients listed for liver transplantation. *Hepatology International vol 1(4) 437-443 doi:10.1007/s12072-007-9035-0*

Gutteling JJ, Duivenvoorden HJ, Busschbach JV, de Man RA, Darlington AE (2010) Psychological Determinants of Health-Related Quality of Life in patients with Chronic Liver Disease. *Psychosomatics 51:157-16 doi:10.1176/appi.psy.51.2.157*

Guyett G.H, Feeny D.H, & Patrick D.L (1993) Measuring Health Related Quality of Life. *Annals of Internal Medicine. Vol 118 No 8* Retrieved from URL:http://www.anesthesia.org/journalclub/references/Quality_of_life/

- Hellgren A, Berglund B, Gunnarsson U, Hansson K, Norberg U & Backman L (1998)
Health Related Quality of Life after Liver Transplantation. *Liver Transplantation and Surgery* Vol 4 No 3 215-221 DOI:10.1002/lt.500040310
- Harper RG, Wager J, Chacko C. (2010) Psychosocial Factors in Non-compliance During Liver Transplant Selection. *Journal of Clinical Psychology in Medical Settings* 17:71-76 DOI:10.1007/s10880-009-9181-8
- Hicks F.D, Larson J.L, Ferrans C.E, (1992) Quality of Life after Liver Transplant *Research in Nursing & Health* Volume 15, Issue 2, pages 111–119, April 10.100
- Hyland M.E, (2003) A brief guide to the selection of quality of life instrument. *Health and Quality of Life Outcomes* 1:24. doi:10.1186/1477-7525-1-24
- Jay CL, Butt Z, Ladner DP, Skaro AI, Abecassis MM (2010) A review of quality of life instruments used in liver transplantation. *Journal of Hepatology* 51(5): 949-959 DOI:10.1016/j.jhep.2009.07.010
- Jenkinson C, Coulter A, & Wright L (1993) Short form 36 (SF 36) health survey questionnaire: normative data for adults of working age. *British Medical Journal* Vol 306 1437-40

Joralemon D, Fujinaga K.M, (1996) Studying the quality of life after organ transplantation: Research problems and solutions. *Social Science and Medicine*. Vol 44, Issue 9, 1259-1296 doi.10.1016/S0277-9536(96)00256-0

Jurado R, Morales I, Taboada D, Denia F, Mingote JC, Jiménez MA, Palomo T, Rubio G, (2010) Coping Strategies and quality of life among liver transplantation candidates, *Psicothema Vol 23 No 1 pp,74-79*

Kanwal F, Gralnek I.M, Hays R.D, Zeringue A, Durazo F, Han S.B, Saab S, Bolus R, Spiegel M.R (2009) Health-Related Quality of Life Predicts Mortality in patients With Advanced Chronic Liver Disease. *Clinical Gastroenterology and Hepatology*. Vol 7 No 7. Retrieved from URL [http://www.cghjournal.org/article/S1542-3565\(09\)00232-8](http://www.cghjournal.org/article/S1542-3565(09)00232-8)

Karademas E.C, Karamvakalis N, Zarogiannos A, (2009) Life context and the experience of chronic illness: is the stress of life associated with illness perceptions and coping? *Stress and Health Vol 25;10.1002*

Kelly M, Chick J, Gribble R, Gleeson M, Holton M, Winstanley J, McCaughan G.W & Haber P.S (2006) Predictors of relapse to harmful alcohol after orthotropic liver transplantation. *Alcohol and Alcoholism Vol 41 No. 3 pp278-283*
doi:10.1093/alcalc/agh257

Kim W.R, (2000) Quality of Life Instruments for Liver Transplant Recipients: Too Many Choices? *Liver Transplantation, Vol 6, No 6;10.1053*

Killneberg P.G & Clavien P-A (2006) *Medical Care of The Liver Transplant Patient, Total Pre-, Intra- and Post-Operative Management (Third Edition)* Blackwell Publishing

Kober B, Kuchler T, Broelsch C, Kremer B, Henne-Bruns D, (1990) A Psychological Support Concept and Quality of Life Research in a Liver Transplantation Program: An Interdisciplinary Multicenter Study *Psychotherapy and Psychosomatics*;54:117-131 (DOI: 10.1159/000288386)

Kraus MR, Schafer A, Csef H, Scheurlen M, Faller H (2000) Emotional State, Coping Styles and Somatic Variables in Patients with Chronic Hepatitis C. *Psychosomatics* 41;377-384

Langenbach M, Schmeisser N, Albus C & Decker O (2008) Comparison of Social Support and Psychosocial Stress After Heart and Liver Transplantation. *Transplantation Proceedings* 40 938-939 doi:10.1016/j.transproceed.2008.03.039

Lazarus S, Folkman RS, (1980) An Analysis of Coping in a Middle Aged Community Sample. *Journal of Health a Social Behaviour* Vol 21 219-239

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York Springer.

Levenson JL, Olbrisch ME, (1993) Psychosocial evaluation of organ transplant candidates. A comparative survey of process, criteria, and outcomes in heart, liver, and kidney transplantation *Psychosomatics*; 34:314-323

Lyons R.A, Wareham K, Lucas M, Price D, Williams J, & Hutchings H.A, (1999)
SF-36 Scores vary by method of administration: implications for study design.
Journal of Public Health Medicine, Vol 21, No.1 41-45 Retrieved from
<http://jpubhealth.oxfordjournals.org/content/21/1/41.full.pdf>

McCormick P.A, O'Rourke M, Carey D, Laffoy M, (2004) Ability to Pay and
Geographical Proximity Influence access to Liver Transplantation even in a
system with universal access, *Liver Transplantation, Vol 10 No 11;10:1422-
1427*

Meichenbaum, D.H., & Turk, D. (1982). Stress, coping and disease: A cognitive- behavioral
perspective. In R.W.J. Neufeld (Ed.), *Psychological stress and psychopathology* (pp.
289-306). New York: McGraw-Hill.

Molinari M, Renfrew P.D, Petrie N.M, De Coutere S & Abdoell M (2010) Clinical
epidemiological analysis of the mortality rate of liver transplant candidates
living in rural areas. *Transplant International doi:10.1111/j.1432-
2277.2010.01200.x*

Mongan D, McCormick P.A, O'Hara S, Smyth B & Long J. (2011) Can Ireland's Increased Rates of Alcoholic Liver Disease Morbidity and Mortality be Explained by Per Capita Alcohol Consumption? *Alcohol and Alcoholism Vol 46, No. 4, p.500 doi: 10.1093/alcalc/arg036*

Moore K.A, Jones H.M, Angus P, Hardy K, Burrows G, (1992) Psychosocial Adjustment to Illness: Quality of Life Following Liver Transplantation, *Transplantation Proceedings, Vol 24 No.5*

Moore K.A, Burrows G.D & Hardy K.J (1997) Anxiety in Chronic Liver Disease: Changes Post Transplantation. *Stress Medicine Vol 13: 49-57*

Moore K.A, Jones R.M, Burrows G.D, (2000) Quality of Life and Cognitive Function of Liver Transplant Patients: A Prospective Study, *Liver Transplantation, Vol 6 No 5;6:633-642*

Nickel R, Wunsch A, Egle, U, Lohse, A.W, Otto G (2002) The Relevance of Anxiety, Depression and Coping in patients after Liver Transplantation. *Liver Transplantation, Vol 8, No 1;8:63-71*

Ogden J (2000) Health Psychology: A Textbook. Second Edition Philadelphia: Open University Press.

- Olbrisch M.E, Benedict S.M, Ashe K, Levenson JL,(2002) Psychological Assessment and Care of Organ Transplant Patients. *Journal of Consulting and Clinical Psychology* Vol 70 No 3 2002;771-783
- Pérez-San-Gregorio M.A, Martín-Rodríguez A, Pérez-Bernal J, Maldonado M.D (2010) Quality of Life in Spanish Patients with Liver Transplant, *Clinical Practice & Epidemiology in Mental Health* Vol 6:6:79-85
- Rainer J.P, Thompson C.H & Lambros H (2010) Psychological and Psychosocial Aspects of The Solid Organ Transplant Experience - A Practice Review. *Psychotherapy Theory, Research, Practice, Training*. Vol 47 No 3, 403-412 DOI:10.1037/a0021167
- Ratcliffe J, Longworth L, Young T, Bryan S, Burroughs A, and Buxton M (2002) Assessing Health-Related Quality of Life Pre- and Post- Liver Transplantation: A Prospective Multicenter Study *Liver Transplantation*;8:263-270.
- Rice PL, (1999) *Stress and Health Third Edition* Brooks Cole 1999
- Robertson G (1999) Individuals' perception of their quality of life following a liver transplant: an exploratory study. *Journal of Advanced Nursing* 30(2) 197-505
- Saab S, Ibrahim A.B, Surti B, Durazo F, Han S, Yersiz H, & Busuttill R.W (2008) Pretransplant variables associated with quality of life in liver transplant recipients. *Liver International* doi;10.1111/j.1478-3231.2008.01831.x

Santos Junior R, Miyazaki M.S, Domingos N.M, Valerio N.J, Silva R.F & Silva R.A (2008)

Patients Undergoing Liver Transplantation: Psychosocial Characteristics, Depressive Symptoms and Quality of Life. *Transplantation Proceedings* 40, 802-804 doi:10.1016/j.transproceed.2008.02.059

Scoring Instructions for the 36-Item Short Form Survey (SF-36). Retrieved from

http://www.rand.org/health/surveys_tools/mos/mos_core_36item_scoring.html

Streisand, R. M., Rodrigue, J. R., Sears, S. F., Perri, M. G., Davis, G. L., & Bamnko, C. G.

(1999). A psychometric normative database for pre-liver transplantation evaluations: The Florida cohort 1991–1996. *Psychosomatics*, 40, 479–48doi.org/10.1016/S0033-3182(99)71185-0

Shuman R, (1996) *The Psychology of Chronic Illness: The Healing Work of Patients,*

Therapists & Families. New York: Basic Books

Starzl T.E, Koep L.J, Schroter P.J, Hood J, Halgrimson C.G, Porter K.A, & Weil R

(1979) The Quality of Life After Liver Transplantation. *Transplant Proceedings* 11(1):252-256

Stilley CS, Miller DL, Tarter RE. (1997) Measuring Psychological Distress in Candidates for

Liver Transplantation: A Pilot Study. *Journal of Clinical Psychology, Vol 53(5)* 459-464

Stilley C.S, Flynn W.B, Sereika S.M, Stimer E.D, Dimartini AF, Devera M.E, (2011)

Pathways of psychosocial factors, stress and health outcomes after liver

transplantation. *Clinical Transplantation* DOI:10.1111/j.1399-

0012.2011.01467.x

Tanikella R, Kawut S.M, Brown R.S, Krowka M.J, Reinen J, Dinasarapu C.R, Trotter J.F,

Roberts K.E, Mohd M.A, Arnett D.K, Fallon M.B (2010) Health Related Quality of

Life and Survival in Liver Transplant Candidates. *Liver Transplant* Vol 16 No

2;10.1002

Taylor S, (2009). *Health Psychology* – Seventh Edition. McGraw-Hill International

Edition 2009.

Telles-Correia D, Barbosa A, Mega I, Monteiro E,(2009) Importance of depression and active

coping in liver transplant candidates' quality of life *Progress in Transplantation*, Vol

19, No. 1 19:85-89

Tome S, Wells J.T, Said A, & Lucey M.R, (2008) Quality of Life after liver

transplantation. A systematic review. *Journal of Hepatology* vol 48 Issue 4

567-577 doi.org/10.1016/j.jhep.2007.12.013

Ubel P.A, Jepson C, Baron J, Mohr T, McMorrow S & Asch D (2001) Allocation of

transplantable organs: Do people want to punish patients for causing their illness?

Liver Transplantation Vol 7 Issue 7 600-607 DOI:10.1053/jlts.2001.25361

- Vere CC, Streba CT, Streba LM, Ionescu AG, Sima F (2009) Psychosocial stress and liver disease status. *World Journal of Gastroenterology* 15(24); 2980-2986
doi:10.3748/wjg.15.2980
- Wainwright S.P, (1997) Transcending chronic liver disease: a qualitative study. *Journal of Clinical Nursing* Vol 6 43-53
- Ware J.E Jr, & Sherbourne C.D (1992) The MOS 36-Item Short-Form Health Survey (SF-36): I Conceptual Framework and Item Selection. *Medical Care*, 30:473-483
- Ware J.E Jr, Kosinski M, Bayliss M.S, McHorney C.A, Rogers W.H, & Raczek A, (1995) Comparison of Methods for the Scoring and Statistical Analysis of SF-36 Health Profile and Summary Measures: Summary of Results from the Medical Outcomes Study. *Medical Care, Vol. 33, No. 4, The Proceedings of the Conference on Measuring the Effects of Medical Treatment* Retrieved from <http://www.jstor.org/stable/3766635> on 2nd February 2012
- Widows M.R, & Rodrigue J.R, (2003) *Clinical Practice Issues in Solid Organ Transplantation In Llwyn S, & Kennedy P, (Eds) Handbook of Clinical Health Psychology, John Wiley & Sons*
- Widows M.R, Jacobsen P.B, Booth-Jones M, Fields K.K, (2005) Predictors of Posttraumatic Growth Following Bone Marrow Transplantation for Cancer. *Health Psychology* Vol 24, No 3, 266-273 DOI: 10.10370278-6133.24.3266

Younossi ZM, McCormick M, Price LL, Boparai N, Farquhar L, Henderson JM, Guyatt G.

(2002) Impact of liver transplantation on health-related quality of life. *Liver*

Transplantaion Nov , Vol. 6, Issue 6, p779-83, -695p

APENDIX A

This questionnaire should only take approx 5-10 minutes to complete. Please try and answer each question as honestly as possible. Thank you for taking the time to complete this survey.

Are you Male or Female?

- Male
- Female

What age are you?

- 18-25
- 26-35
- 36-45
- 46- 55
- 56-65
- Over 65

What is your Marital Status?

- Single
- In a Relationship
- Married
- Divorced/Separated
- Widowed

What is your employment Status?

- Employed Fulltime
- Employed Part time
- Unemployed
- Student

What county do you live in? And what part of the county? (eg Dublin West, Kerry South)

Do you live in an urban or rural area?

- Urban
- Rural

What is your transplant status?

- Post Transplant
- Pre Transplant

If you are post-transplant, How long has it been since you received your transplant?

4) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- | | Yes | No |
|---|---|--------------------------|
| a Cut down on the <u>amount of time</u>
you spent on work or other activities | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |
| b <u>Accomplished less</u> than you
would like | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |
| c Were limited in the <u>kind</u> of work
or other activities | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |
| d Had <u>difficulty</u> performing the
work or other activities (for
example, it took extra effort) | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |

5) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- | | Yes | No |
|---|---|--------------------------|
| a Cut down on the <u>amount of time</u>
you spent on work or other
activities | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |
| b <u>Accomplished less</u> than you
would like | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |
| c Did work or activities <u>less</u>
<u>carefully than usual</u> | <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> |

6) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- | | | | | |
|-------------------------------------|-----------------------------------|-------------------------------------|--------------------------------------|------------------------------------|
| Not at all <input type="checkbox"/> | Slightly <input type="checkbox"/> | Moderately <input type="checkbox"/> | Quite a bit <input type="checkbox"/> | Extremely <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7) How much bodily pain have you had during the past 4 weeks?

- | | | | | | |
|-------------------------------|------------------------------------|-------------------------------|-----------------------------------|---------------------------------|--------------------------------------|
| None <input type="checkbox"/> | Very Mild <input type="checkbox"/> | Mild <input type="checkbox"/> | Moderate <input type="checkbox"/> | Severe <input type="checkbox"/> | Very Severe <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- | | | | | |
|-------------------------------------|---------------------------------------|-------------------------------------|--------------------------------------|------------------------------------|
| Not at all <input type="checkbox"/> | A little bit <input type="checkbox"/> | Moderately <input type="checkbox"/> | Quite a bit <input type="checkbox"/> | Extremely <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

9) These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks.....

10) During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting friends, relatives, etc.)?

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?						
b. Have you been a very nervous person?						
c. Have you felt so down in the dumps that nothing could cheer you up?						
d. Have you felt calm and peaceful?						
e. Did you have a lot of energy?						
f. Have you felt downhearted and blue?						
g. Did you feel worn out?						
h. Have you been a happy person?						
j. Did you feel tired?						

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

11) How TRUE or FALSE is **each** of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am as healthy as anybody I know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I expect my health to get worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My health is excellent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.

1 2 3 4

2. I've been concentrating my efforts on doing something about the situation I'm in.

1 2 3 4

3. I've been saying to myself "this isn't real."

1 2 3 4

4. I've been getting emotional support from others.

1 2 3 4

5. I've been giving up trying to deal with it.

1 2 3 4

6. I've been taking action to try to make the situation better.

1 2 3 4

7. I've been refusing to believe that it has happened.

1 2 3 4

8. I've been saying things to let my unpleasant feelings escape.

1 2 3 4

9. I've been getting help and advice from other people.

1 2 3 4

10. I've been trying to see it in a different light, to make it seem more positive.

1 2 3 4

11. I've been criticizing myself.

1 2 3 4

12. I've been trying to come up with a strategy about what to do.

1 2 3 4

13. I've been getting comfort and understanding from someone.

1 2 3 4

14. I've been giving up the attempt to cope.

1 2 3 4

15. I've been looking for something good in what is happening.

1 2 3 4

16. I've been making jokes about it.

1 2 3 4

17. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

1 2 3 4

18. I've been accepting the reality of the fact that it has happened.

1 2 3 4

19. I've been expressing my negative feelings.

1 2 3 4

20. I've been trying to find comfort in my religion or spiritual beliefs.

1 2 3 4

21. I've been trying to get advice or help from other people about what to do.

1 2 3 4

22. I've been learning to live with it.

1 2 3 4

23. I've been thinking hard about what steps to take.

1 2 3 4

24. I've been blaming myself for things that happened.

1 2 3 4

25. I've been praying or meditating.

1 2 3 4

26. I've been making fun of the situation.

1 2 3 4

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0 1 2 3 4

Thank you for taking part.

(removed patient consent forms to preserve anonymity)