The Evolution Of Sleep-Onset Latency Problems:

An Experimental Investigation Of Pre-Sleep Cognition And

Attribution In People With Cancer

And Research Portfolio

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# 1. Research Case Study

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# 1. Literature Review

Cognitive Arousal in Sleep-Onset Insomnia and the Relationship to Sleep

Disturbance in Cancer Populations: A Review of The Literature

Written in accordance with the guidelines for submission to British Journal of Health Psychology (Appendix 1.1)

#### **ABSTRACT**

**Objective.** Cognitive arousal is associated with insomnia and sleep problems often develop following stressful life events, such as a cancer diagnosis. However, cognitive arousal in this population group has not been widely investigated. The aim of this study therefore, is to review the main literature in these areas and to generate additional questions for future research.

**Methods.** Electronic databases and bibliographies of review articles were searched for studies into the areas of relevance for this review.

Results. Investigation of the insomnia literature in the general population suggests that presleep cognition and attribution play a role in the development of insomnia. Studies into insomnia and cancer were sparse and of variable quality but nevertheless highlighted a high incidence of sleep disturbance within this population group. Sleep disturbance in cancer populations is thought to be related to medical variables although the insomnia literature suggests that cognition and attribution may be the primary cause of sleep disturbance within this population group.

Conclusions. Research is required to establish whether cognition and attribution is related to the development of sleep disturbance following stressful life events such as cancer. The emotional Stroop task was proposed as a potential measure for assessing cognition and attribution in insomnia. This could have implications for the mechanisms involved in the evolution of sleep problems and for the type of psychological intervention that would be effective in preventing the development of sleep disturbance.

#### INTRODUCTION

Although there has been many important studies over the past two decades into insomnia within the general population, there has been a dearth of research regarding the incidence, nature and management of insomnia within medical populations such as cancer. A recent study by Miaskowski and Lee (1999) found that oncology patients receiving radiotherapy obtained a mean sleep efficiency index of 70.7% estimated by wrist actigraphy. However, despite the high incidence of sleep disturbance in this population group, "understanding the relationship of insomnia to cancer is an area of investigation that seems to have lagged behind, while our understanding and treatment of sleep disorders advances" (Silberfarb et al., 1993, p.997).

The primary aim of this paper is to review the literature identified from electronic databases and bibliographies of review articles on: cognitive arousal and sleep disorders; the relationship between attentional bias and cognitive arousal; insomnia in cancer; and the impact of transitory mental load, such as stress, on sleep-onset latency problems. An additional aim will be to review psychosocial oncology studies in order to highlight potential links between these studies and insomnia within cancer populations. It is hoped that this will help establish what factors are associated with the development of insomnia following stressful life events, and to generate additional research questions for future studies.

## Cognitive Factors in Sleep

Research into the aetiology of insomnia in the general population over the past two decades has investigated the influence of pre-sleep cognitive, and physiological, arousal on the ability to sleep. Evans (1977) was among the first to recognise that people complain of mental alertness in bed more than physiological arousal, a finding which has been

supported by several studies. Lichstein and Rosenthal (1980) for example, found that 55% of insomniacs attributed their disturbed sleep solely to cognitive arousal whereas only 5% attributed it to somatic arousal. Nicassio et al., (1985) developed the Pre-Sleep Arousal Scale and found that cognitive arousal was more highly correlated with sleep-onset latency than somatic arousal providing further evidence of the impact of pre-sleep cognitive arousal on the ability to sleep.

Investigations of pre-sleep thoughts have therefore highlighted the importance of cognitive arousal in the development and maintenance of sleep disturbance. Van Egeren et al. (1983) used tape recordings of thoughts occurring prior to a prompting tone during the pre-sleep period of students with sleep-onset insomnia. They found that pre-sleep cognition measured in the laboratory were significantly associated with subjective sleep-onset latency, but not with objective sleep-onset latency. Studies which have also focused on inducing sleep disturbance by manipulating pre-sleep cognitive intrusions in the pre-sleep period have resulted in significantly longer latency to sleep-onset difficulties. Gross and Borkovec (1982) for example, found that in good sleepers, experimental manipulations aimed at increasing cognitive intrusions in the pre-sleep period led to significantly longer latency to sleep-onset according to EEG criteria. A study by Harvey (2000) into sleep hygiene and sleep-onset insomnia, found that cognitive interference accounted for 51% of the varience in sleep quality which again emphasised the importance of cognitive arousal.

The study of pre-sleep cognition has highlighted that the pre-sleep thoughts of insomniacs are more negative than those of normal sleepers (Borkovec, 1982). Coyle and Watts (1991) demonstrated that although sleep dissatisfaction is a multi-faceted problem, high levels of worry and rumination were among the principal characteristics of sleep maintenance problems. Nicassio et al. (1985) also found that insomniacs tended to experience more

negative thoughts in the pre-sleep period than good sleepers. A similar finding was reported by Kuisk et al. (1989) who investigated the content of thoughts during the pre-sleep period and found that insomniacs reported more negative thoughts than controls. Affect-laden pre-sleep cognition therefore appears to be the most likely to become intrusive upon sleep. A recent theoretical review has also suggested that it is not the thoughts *per se* that are untypical but the meaning or concern individuals attribute to them (Espie and Wicklow, 1998).

Recent studies have begun to investigate the content and type of thoughts that are most likely to be associated with the continuation of insomnia, and indicate that the uncontrollable negative thoughts associated with insomnia are actually centred around the problems they are having with their sleep. Borkovec (1982) found that people with insomnia report a greater number of intrusive thoughts about their sleep. Watts et al. (1995) demonstrated that insomnia was related to the presence of sleep-related thoughts, whereas worry was associated with more general thoughts. A recent study by Wicklow and Espie (2000) investigated the nature and content of pre-sleep thoughts of insomniacs according to the three systems model of arousal based on cognitive and somatic arousal, and environmental stimulation. Cognitive arousal comprised almost half of all pre-sleep mental activity. Thoughts about sleep and its consequences, the cognitive sleep category, comprised 20% of all thought segments. Thoughts in the cognitive sleep category coupled with thoughts about planning and problem solving therefore significantly contributed to disturbed sleep-onset latency. This suggested that insomniacs had a preoccupation with the inability to fall asleep and the effect this may have on their mood and daytime performance. Consequently, studies have demonstrated that a major concern for insomniacs is the perceived loss of control over how and when they will fall asleep, and the anticipated effects that a lack of sleep will have on their level of daily functioning.

Further evidence for the potential mechanisms involved in the development of sleep related concerns and thoughts was provided by Ansfield et al. (1996). This study explored the effects of different sleep-onset instructions on sleep-onset latency of normal sleepers under either a high or low mental load. There was evidence of paradoxical wakefulness for those participants attempting to fall asleep quickly under a high mental load. This finding was related to Wegner's (1994) theory of a self-loading system where the thwarted desire for mental control becomes the source of mental incapacitation that produces the opposite desired state of mind. They hypothesised that failure to fall asleep on a few occasions could occur when sleep is attempted under transitory mental loads, such as a time of stress. Eventually a person's pre-sleep thoughts about not being able to sleep under these conditions could come to constitute a chronic and debilitating mental load which, when combined with the continuing and long-frustrated desire to fall asleep, could lead to chronic insomnia. Ansfield et al. (1996) proposed that this finding is largely consistent with theories of cyclic escalation of anxiety disorders (Ascher, 1981) and worry about sleep (Borkovec, 1982).

Wegner's (1994) model also has particular parallels with the cognitive model of insomnia proposed by Espie and Wicklow (1998) and the findings of Wicklow and Espie (2000) which highlights the role of cognitive content on the evolution of insomnia. This model suggests that the typical insomniac may not be well prepared for sleep which leads to increased pre-sleep cognitive arousal. Espie and Wicklow (1998) suggested that in order for successful de-arousal, which is necessary to facilitate sleep, it is desirable to achieve a state of: minimal processing of information, which relates to mental alertness in bed; minimal cognitive drive, which refers to the content of thinking; minimal effort associated with sleep processes; and minimal affective load, such as the reduction of concern or anxiety related to daytime life or sleep itself. Sleep attempted under transitory mental loads may therefore

lead to an increase in the four cognitive states highlighted above resulting in increased sleep disruption. The cognitive content in some individuals may then begin to focus on the perceived failure to sleep, as highlighted in Ansfield et al.'s (1996) study, which may lead to a continuation in pre-sleep cognitive tasks thus leading to further sleep disruption. Consequently, an analysis of cognitive content may help determine why some individuals develop persistent insomnia after failure to sleep following a time of stress.

# Cancer and Sleep

Cancer is a stressful life event which is often associated with sleep disturbance. A pilot study by Beszterczey and Lipswski (1977) was among the first to find evidence to support anecdotal reports that patients with cancer commonly develop insomnia. This early research found that sleep was more severely affected in cancer patients than in the general population and in patients with non-malignant medical conditions. Derogatis (1979) also reported that hypnotics were the most frequently prescribed psychotropic medication and accounted for 48% of the total psychotropic medications within this population group. In a more recent study by Engstrom et al. (1999), sleep patterns in breast and lung cancer patients were investigated using an 82-item telephone survey and found that 44% of patients reported difficulties with their sleep in the month prior to interview. Silberfarb et al. (1993) investigated the sleep architecture of breast and lung cancer patients, insomniacs, and normal sleepers and found that lung cancer patients slept as poorly as the insomniac group. Sleep improvement was also rated as one of the primary aims of cancer pain relief efforts by the World Health Organisation (WHO, 1986) thus providing further evidence that sleep disturbance is often associated with cancer.

The effects of sleep disturbance have particular implications for cancer patients as insomnia often results in fatigue and irritability, can affect daytime mood and performance, and is

postulated to be a risk factor for the development of clinical anxiety and depression (e.g. Ford and Kamerow, 1989). Owen et al. (1999) highlighted that sleep disturbance in cancer patients resulted in more daytime dysfunction than in healthy controls. Sleep has also been associated with tissue restoration (Oswald, 1980) and pain tolerance (Chuman, 1983). Laboratory data has demonstrated that various immune functions show changes during sleep and that sleep may contribute to optimal functioning of the immune system (Da-Shih and Silberfarb, 1991).

Sleep disturbance therefore, has particular implications for those who are physically ill. Pressman et al. (1997) indicated that sleep disruption may affect not only mental status and cognitive functioning but also the course, treatment, and recovery from medical disorders. However, Walsleben (1997) stated that "all too often, patients and clinicians assume that the primary disease is the cause of all symptoms and overlook the impact of sleep" (p. 369). Moreover, although sleep disturbance may be diagnosable in almost every medical subspecialty (e.g., Walsleben, 1997; Pressman et al., 1997), and is recognised in the International Classification of Sleep Disorders (1997), there has been little research into the psychological and physiological intervening variables.

The cause of sleep disturbance in medical populations is often attributed to pain (Da-Shih and Silberfarb, 1991), disease variables (Silberfarb et al. 1993), and side effects of treatment (Da-Shih and Silberfarb, 1991). Factors such as the hospital environment, medication, surgery, and procedures have also been proposed as causes of sleep disruption associated with medical disorders (e.g. Pressman, et al 1997). Very few studies have investigated the role of psychological factors although the effects of depression and anxiety (e.g. Ford et al. 1995) has been proposed as a contributing factor to the development of sleep disturbance after a cancer diagnosis (e.g., Beszterczey and Lipswski, 1977). When

insomnia is a primary complaint in the absence of any illness, there appears to be an assessment of possible precursors such as stressful life-events. However, when insomnia is secondary to illness, an attribution appears to be made which precludes a search for any additional causes (Stam and Bultz, 1986). As noted by Silberfarb et al. (1993), complex physiological, immunologic, anatomic, and emotional factors may all play a role in maintaining sleep disturbance and therefore all of these factors require investigation.

Few studies therefore, have investigated psychological factors and more specifically, why insomnia often persists in a proportion of individuals after the primary medical condition and associated factors have been resolved. Tjemsland et al. (1998) for example, found one third of breast cancer patients continued to have trouble falling asleep at one year since surgery compared to half of the patients at six weeks because thoughts or images about the illness kept coming into their minds as they attempted to fall asleep. A more recent study by Smith et al. (2000) investigated sleep disturbance in chronic pain patients and found that pre-sleep cognitive arousal, rather than pain, was found to be the primary predictor of sleep quality.

Studies into cancer and insomnia have suggested that insomnia secondary to illness may not be experienced as qualitatively different from insomnia associated in the absence of illness (Stam and Bultz, 1986). Da-Shih and Silberfarb (1991) also noted that the management of insomnia in cancer patients may essentially be an extension of general principles used to treat sleep disorders in other population groups. Therefore, study of sleep disorders in individuals with cancer may provide important information regarding the development of insomnia following a stressful life event.

#### Cognitive Arousal and Cancer

Many studies have demonstrated that cognitive arousal often accompanies stressful life events and can lead to psychological disorders such as post-traumatic stress disorder (PTSD). Recent studies have found evidence of PTSD symptoms (i.e. intrusive thoughts and avoidance) in cancer populations (e.g. Baider and De-Nour, 1997; Cordova et al., 1995). Andrykowski and Cordova (1998) assessed PTSD symptoms and quality of life in 55 women with breast cancer and found that PTSD symptoms may be reasonably high in survivors of breast cancer. Baider and De-Nour (1997) explored PTSD symptoms of 283 patients with stage I and stage II breast cancer and found a strong link between cognitive intrusions and psychological distress. Epping-Jordan et al. (1994) also highlighted that "avoidance and intrusive thoughts may be more sensitive indices of cognitive/affective and psychological responses to the stress associated with cancer diagnosis and treatment than are measures of generalised psychological distress" (p.541).

Intrusive memories have also been associated with increased levels of maladaptive coping and prolonged psychopathology. Cella and Tross (1986) studied 60 men with Hodgkin's disease who had been free of the disease and all treatment for six months, and an agematched sample of 20 healthy men, in order to study the psychosocial sequelae of successful cancer treatment and found greater levels of psychosocial dysfunction in the cancer sample. Kaiser et al. (1993) found a high frequency of psychological distress in cancer patients with advanced disease, and that the majority of patients reported recurrent and intrusive recollections of the cancer treatment. Half of the patients also reported distressing dreams and avoided anything associated with cancer. A recent study by Parle et al. (1996) assessed 2 groups of newly diagnosed cancer patients, 4-6 weeks and 1 year after diagnosis, to assess the effects of appraisals, coping responses, and resolution of any concerns on subsequent mental health. The importance of appraisal in the coping process

was strongly supported, with high threat appraisal leading to later affective disorder and subsequent psychological distress. All of the above studies therefore, have highlighted that a large proportion of individuals with cancer experience increased cognitive arousal which has been proposed in the insomnia literature as a contributing factor to sleep disturbance.

#### Attentional Bias

Cognitive models of emotional disorders assume that attentional bias plays a vital role in causation and maintenance of psychological distress. Central to the cognitive theory of psychopathology is that individuals with emotional disorders have a preoccupation with threatening stimuli in their environment due to an information processing bias (Williams et al., 1996). In PTSD for example, attention is drawn to stimuli that remind the individual of the past trauma which exacerbates the fear of future similar events. This attentional bias is seen as a major contributing factor in the development and maintenance of emotional disorders whereby small increases in emotional disturbance leads to the increased saliency of certain stimuli with subsequent additional increases in emotional distress.

This cyclic escalation of emotional distress therefore has parallels with the studies outlined above into the development of insomnia, such as Ansfiled (1996), which suggest that insomnia is due to biases in attention towards past experiences of the failure to sleep. Presleep cognitive content may first be focused on a stressful life event which subsequently leads to increased cognitive arousal and decreased ability to sleep. However, the individual's perceived failure to sleep under these conditions may then become the focus of attention leading to persistent sleep disruption. The theory of information processing bias therefore has particular implications for the study of sleep disorders whereby attention is drawn to stimuli that remind the individual of past failures and consequences of the inability to fall asleep.

Although attentional bias has not been widely investigated in relation to sleep disorders, the study of information-processing biases in emotional disorders has become increasingly popular (Pincus, 1998) due to increased interest in cognitive accounts of emotion. Two broad strategies have generally been employed to study cognition in emotionally disordered patients. One method investigates thought content through interviews and questionnaires and the second method has involved the application of cognitive psychology methods (McNally et al., 1990). Questionnaire and interview methods are often restricted to conscious cognition and introspection and are completed retrospectively. This has consequently led to an increase in experimental studies based on cognitive psychology methods. One of the main methodologies has been an emotional analogue of the Stroop task (Stroop, 1935) where the automatic processing of word meaning interferes with colour naming. This test is thought to be an indirect way of assessing cognitive bias, without the inherent difficulties of self-report measures, and has been described as the as the 'hallmark' measure of attention (McLeod, 1991).

The emotional Stroop task has been used to assess cognitive bias in a wide range of clinical conditions (Williams et al., 1996) such as PTSD (McNally et al., 1990), agoraphobia (Hayward et al., 1994) and panic disorder (McNally et al., 1994). It has also been used recently to assess attentional bias in medical conditions such as chronic pain (Pincus et al., 1998). A study by McLeod and Hagan (1985) used a modified emotional Stroop task to investigate patients' patterns of processing selectivity and subsequent emotional response to a colonoscopy. Studies have used both card and computer presentations with both methodologies producing replaceable effects (Williams et al., 1996). Consequently, it has been well established that the emotional Stroop task is a useful measure for assessing the extent to which attentional bias is involved in the maintenance of emotional disorders in a wide range of population groups (Williams et al., 1996).

It could be argued therefore, that the emotional Stroop task could have important implications for the study of cognitive factors in the evolution of sleep disorders. The above literature would suggest that there may be a difference in the attentional bias of those individuals who have recently developed normative, transient sleep disturbance after a life event as opposed to individual who have gone on to develop long-term sleep disturbance. If the Stroop task was to be used with individuals with cancer who have developed insomnia, the literature would suggest that words related to cancer would be more salient than insomnia related words in a group of cancer patients who have recently developed transient insomnia. However, those who have gone on to develop persistent insomnia may have a relatively higher bias in attention towards insomnia related words. This is an area that warrants further investigation as this may have particular implications for the role of cognitive therapy in the prevention of the development of persistent insomnia following stressful life events.

#### Summary

The results of this review have been discussed in terms of cognitive arousal in insomnia, insomnia in cancer, the relationship between attentional bias and psychological disorders, and the links between these studies. The use of the emotional Stroop task has been proposed as a potential measure of cognitive bias in sleep disorders to support existing questionnaire findings. Studies specifically investigating the factors associated with sleep problems in cancer is sparse, despite the growing literature on insomnia within the general population. The insomnia literature, coupled with studies into information processing biases in psychopathology, suggests that pre-sleep cognitive arousal and attribution may be a central factor in the development of insomnia.

Due to the high prevalence of sleep disturbance within cancer populations, individuals with cancer may be a suitable group for investigating the role of attribution and cognition in insomnia. Research would be beneficial to establish whether pre-sleep thoughts and information-processing biases are related to the development and maintenance of sleep disturbance within cancer, and other population groups. The use of measures such as the emotional Stroop task, together with questionnaire measures of psychological distress and pre-sleep cognitive intrusions, may provide information regarding the role of cognition in the development and maintenance of sleep disorders. This could have important implications for the mechanisms involved in the evolution of sleep problems and consequently, for the types of psychological interventions that would be effective in preventing the development of long-term insomnia in individuals with cancer, and other population groups.

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# 2. MAJOR PROJECT PROPOSAL

The Evolution Of Sleep-Onset Latency Problems:

An Experimental Investigation Of Pre-Sleep Cognition And Attribution In

People With Cancer

#### **SUMMARY**

Cognitive arousal has been found to be a central factor in insomnia and recent research has begun to investigate the types of pre-sleep thoughts that are the most intrusive upon the ability to fall asleep. Sleep problems are often associated with stressful life events and the purpose of this study is to look at the types of pre-sleep thoughts that occur after one such stressful life event, a cancer diagnosis. The aim is to investigate the types of thoughts that may be associated with the development and maintenance of sleep-onset latency (SOL) problems in a cancer population. The proposed study aims to investigate this by recruiting two groups of volunteers from the Beatson Oncology Centre, Glasgow: (1) cancer patients with SOL problems within three months of diagnosis and; (2) cancer patients with SOL problems 12-18 months from diagnosis. It is hypothesised that findings will have important implications for the mechanisms involved in the evolution of sleep problems and consequently for the types of psychological interventions that would be effective in preventing the continuation of sleep problems after a significant life event such as cancer.

# **INTRODUCTION**

# Cancer and Sleep

Previous research has indicated that there is a high incidence of insomnia in cancer populations (e.g. Silberfarb et al., 1993). Insomnia can affect an individual's quality of life as it often results in subsequent fatigue and irritability and is postulated to be a risk factor for the development of anxiety and depression (e.g. Ford et al., 1995). Sleep has also been associated with tissue restoration (Oswald, 1980), pain tolerance (Chuman, 1983), and the immune system which has important implications for cancer patients. Silberfarb et al. (1993) indicated that the relationship of insomnia to cancer is an area that has lagged behind while knowledge about sleep disorders advances.

## Cognitive Factors in Sleep

Cognitive (i.e. mental) arousal has been found to be a central factor in insomnia. Lichstein and Rosenthal (1980) found that 55% of insomniacs attributed their disturbed sleep solely to cognitive arousal whereas only 5% attributed it to somatic (i.e. physical) arousal. Nicassio et al. (1985) developed the Pre-Sleep Arousal Scale and also found that cognitive arousal was more highly correlated with SOL than somatic arousal. Coye and Watts, 1991 also demonstrated that affect-laden cognitions are the most likely to become intrusive upon sleep.

Recent studies have begun to investigate the types of thoughts that are most likely to be associated with insomnia and indicate that the uncontrollable thoughts associated with insomnia are actually centred around the problems people are having with their sleep. Borkovec (1982) found that people with insomnia report a greater number of intrusive thoughts about their sleep. Watts et al. (1995) found that insomnia was related to the presence of sleep-related thoughts whereas worry was associated with more general thoughts. Wicklow and Espie (2000) investigated the nature and content of pre-sleep thoughts of insomniacs according to the three systems model of arousal based on cognitive somatic arousal, and environmental stimulation. Thoughts about sleep itself, and rehearsal/planning/problem solving, and thoughts about the quality of thinking were the most likely to intrude upon the sleep onset period. Annsfield et al. (1996) also suggested that the uncontrollable obsessive thoughts of insomniacs are centred around the problems they are having with their sleep. They proposed that failure to fall asleep on a few occasions could occur when sleep is attempted under transitory mental loads, such as a time of stress, which prompts pre-sleep rumination. The inability to sleep might be prompted by such events, and only later become a response to the perceived failure to sleep, when thoughts about their inability to sleep then come to constitute a debilitating mental load.

### Life Events and Sleep

DSM IV includes a life threatening illness as a possible criterion for post traumatic stress disorder (PTSD) which is often associated with sleep problems. Many studies have found evidence of PTSD symptoms (i.e. intrusive thoughts and avoidance) in cancer populations (e.g. Baider et al., 1997: and Cordova et al., 1995) especially after diagnosis. Despite the limited research in this area, current literature suggests that sleep problems continue in a proportion of patients after the initial trauma resolves. Tjemsland et al. (1998) for example, looked at PTSD symptoms in cancer patients six weeks and one year after surgery for breast cancer and noted that one-third of patients had trouble falling asleep at one year compared to half at six weeks because thoughts or images about the illness kept coming into their mind. Intrusive thoughts about cancer therefore appeared to have an impact upon SOL, especially early after diagnosis.

### Psychosocial Oncology Studies

Additional studies have investigated the persistence of other psychological problems triggered by cancer at different time points after diagnosis. Brewin et al. (1996), for example, investigated the persistence of intrusive memories in a depressed cancer population, and Cella and Tross (1986) studied groups of patients from time since cancer treatment in order to study the psychosocial sequelea of successful cancer treatment. A study by McLeod and Hagan (1991) used a modified emotional Stroop task, a measure often used to assess attentional bias, to investigate patients' patterns of processing selectivity and subsequent emotional response to a stressful life event, a colonoscopy. A recent study by Parle et al. (1996) assessed two groups of cancer patients, six weeks and one year after diagnosis to assess the effects of appraisals, coping responses, and resolution of any concerns on subsequent mental health. Therefore, although the persistence of psychological problems triggered by cancer has been widely investigated, few studies have

specifically investigated the persistence of sleep problems in this population group. In addition, no studies have investigated the types of pre-sleep thoughts that are specifically associated with the development and maintenance phases of sleep problems after a traumatic life event. Current literature suggests that pre-sleep intrusive thoughts relating to cancer and illness would be the most likely, initially, to intrude upon sleep as these are the most affect-laden. However, a central factor in the evolution of insomnia after a life event appears to be whether the pre-sleep thoughts associated with the initial trauma then generalise to thoughts centred around the inability to get to sleep.

#### Attentional Bias

Two broad strategies have generally been employed to study cognition in emotionally disordered patients. One method investigates thought content through interviews and questionnaires and the second method has involved the application of cognitive psychology methods (McNally et al., 1990). Questionnaire and interview methods are restricted to conscious cognition and introspection. This has consequently led to an increase in experimental studies based on cognitive psychology methods. One of the main methodologies has been an emotional analogue of the Stroop task (Stroop, 1935) where the automatic processing of word meaning interferes with colour naming.

The emotional Stroop task could have important implications for the study of cognitive factors in the evolution of sleep disorders. The above literature would suggest that there may be a difference in the attentional bias of those individuals who have recently developed transient sleep disturbance after a life event as opposed to individuals who have gone on to develop long-term sleep disturbance. If the Stroop task was to be used with individuals with cancer who have developed sleep disturbance, the literature would suggest that words related to cancer would be more salient than insomnia related words in a group of cancer

patients who have recently developed transient sleep disturbance. However, those who have gone on to develop long-term sleep disturbance may have a relatively higher bias in attention towards insomnia related words.

The purpose of this study is to assess attribution and cognition in a cancer population by using the emotional Stroop task. This has important implications for implementing early brief interventions within this, and possibly other population groups. This could help prevent the continuation and development of insomnia often associated with cancer which would consequently decrease the risk of developing other psychological disorders such as depression or anxiety. This may also have implications for the proposed links in the current literature about the relationship between insomnia and other factors, such as pain and side effects of drugs, in cancer populations.

## **AIMS AND HYPOTHESES**

The aim of this study is to investigate the evolution of sleep problems after a diagnosis of cancer by examining the type of pre-sleep thoughts associated with SOL problems in two separate cancer groups: 0-12 weeks after diagnosis (early group); and 12-18 months after diagnosis (late group). These groups were chosen based on Tjemsland et al.'s (1998) study.

The underlying hypothesis in this study is that there will be a difference in the early and late groups in terms of the types of pre-sleep cognition associated with SOL problems. The main hypotheses are:

- 1. There will be no significant difference in overall level of pre-sleep mental arousal between the two groups;
- 2. Both groups will have higher levels of pre-sleep mental arousal than somatic arousal;

- 3. The early group will attend more to cancer/illness related words and the late group attend more to sleep/insomnia related words;
- 4. There will be a higher incidence of pre-sleep thoughts relating to sleep in the late group;
- 5. There will be a higher incidence of pre-sleep thoughts relating to cancer/illness in the early group.

## **PLAN OF INVESTIGATION**

#### **DESIGN**

The most suitable type of study to test the hypothesis outlined in this study would be a prospective study. However, due to time constraints, together with the fact that this is a preliminary test of a hypothesis, this study will be cross-sectional. It is hoped that experimental control will be addressed by matching subjects in the early and late group for sex, age and tumour type.

## **SUBJECTS**

Volunteers will be recruited from the Beatson Oncology Centre from different cancer groups. Due to the fact that this study is a preliminary test of a hypothesis there is no direct comparison study from which to conduct a power calculation. The best available study, which included a Stroop measure that would be sensitive enough to detect differences on a repeated measure ANOVA, was a study by McNally et al. (1994). This paper used the Stroop to investigate the differential processing of threatening information of people with conditioned anxiety. Using data from this study as the best estimate, a minimum of 21 subjects per group would be required to detect significant differences at p<0.01, or 11 subjects per group at p<0.05, on a repeated measures ANOVA with 0.8 power (1-tailed). This study therefore aims to recruit 21 subjects in each group although 11 in each group would meet the required numbers identified by using a lower significance level of 0.05. A

matched design will also reduce heterogeneity between subjects and therefore this sample size should be adequate.

- Common Inclusion Criteria
- 1. Are aged 16-65 years;
- Significant difficulty getting to sleep, i.e. a minimum SOL of 30 minutes, 4 times per week (International Classification of Sleep Disorders, 1997).
- Common Exclusion Criteria
- 1. Prior history of sleep problems;
- 2. Active psychological or drug interventions for sleep problems;
- 3. Evidence of night wakening without any difficulty falling asleep.
- Additional Inclusion Criteria for the Early Group
- 1. Recent diagnosis of cancer (approximately 0-12 weeks)
- Additional Inclusion Criteria for the Late Group
- 1. Cancer diagnosis 12-18 months previously;
- 2. If they can recall having SOL problems 0-12 weeks post-diagnosis.

## **MEASURES**

## **SCREENING**

1. Assessment of whether SOL is over 30 minutes 4 times per week as measured by self-report.

#### ASSESSMENT OF COGNITION

- 1. **Pre-Sleep Arousal Scale (PSAS)** Nicasso et al. (1985) This is a self-administered questionnaire to assess cognitive and somatic arousal as patients fall asleep.
- 2. Emotional Stroop Measure. The emotional Stroop task is a recognised accepted measure that has often been used in previous studies to measure attentional bias in various subject groups (McLeod, 1985). The Stroop paradigm (Stroop, 1935) requires subjects to name the ink colour in which words are presented while attempting to ignore the meaning of the word. It is designed to compare colour-naming speed for sets of neutral words with colour-naming speed of emotive words. The colour-naming speed is a measure of the interference effect of the word's content on the performance of the task. This is therefore a measure of attentional bias due to the interference effect for colour-naming. Adapted computerised emotional Stroop measures have also been widely used to assess for attentional bias in a range of disorders as reaction time can be recorded very accurately.

An emotional Stroop measure has been developed for this study (see appendix 2.1) and will be presented on a laptop computer using Superlab Pro software, a standard package for developing psychological tests. This measure contains a list of 80 words presented in four colours: blue; yellow; green; and red. The 80 words consist of 40 target words (20 relating to cancer and 20 relating to insomnia) and 40 neutral words. The target words were chosen from review of studies into insomnia and psychosocial oncology literature. They were also derived from typed transcripts from Wicklow and Espie's (2000) study investigating pre-sleep thoughts in insomnia and a current psychosocial oncology study at the Beatson Oncology Centre (Reference 98/222(2)). Neutral words were taken from a

thesaurus and matched to target words in terms of syllable and word length and also frequency of occurrence in the English language.

3. Sleep-Onset Thought Scale (SOTS) - This questionnaire has been developed to assess the frequency and intrusiveness of insomnia and cancer related cognitions during the sleep-onset period. There are two versions of this measure, one for the early group and one for the late group. Both scales include 8 insomnia and 8 cancer related items but the tense has been changed for the late group (see Appendix 2.2 & 2.3). The items for the sleep related cognitions has been derived from the two main factors identified from the analysis of Wicklow and Espie's (2000) study. These two factors were rehearsing/planning and problem solving, and sleep and its consequences. Items have been proportionately based on these two factors. Cancer related cognitions have been derived from previous psychosocial oncology studies and from personal communication with Clinical Psychologists working within cancer populations.

## **ADDITIONAL MEASURES**

- 1. **Impact of Events Scale (IES)** (Horowitz et al, 1979): This standardised questionnaire aims to assess levels of avoidance and intrusiveness following a traumatic event, in this case the cancer diagnosis.
- 2. General Health Questionnaire 12 (GHQ12) (Goldberg and Williams, 1978): This standardised measure aims to assess levels of psychological distress in both groups.
- 3. **Thought Control Questionnaire (TCQ)** (Wells and Davis, 1994); This questionnaire aims to identify thought control strategies for unwanted intrusive thoughts in both groups.

## **PROCEDURE**

Cancer patients with SOL problems approximately 3 months and 18 months after diagnosis, will be identified from a variety of recruitment methods to maximise response rate. It is anticipated that the two principal methods of recruitment will be through Consultants, and leaflets advertising for people who have developed sleep problems since a cancer diagnosis. If possible, potential subjects from the early and late group will be matched according to age, gender, and tumour type. They will interviewed by Lynne Taylor (Trainee Clinical Psychologist) at the Beatson Oncology Centre to identify if sleep-onset problems are evident and to assess for any exclusion criteria. The nature and procedure of the study will be explained to suitable subjects and an information sheet (see Appendix 2.4) will be provided. The patients willing to be included will be asked to sign a consent form (see Appendix 2.5) and will have the opportunity to ask any questions. The patients will then be asked to complete the GHQ12, PSAS, TCQ, IES, PC based Stroop measure and the SOTS. It is anticipated completion of the above measures will take approximately 30-40 minutes. If any of the scores on the IES or GHQ12 are particularly high the appropriate consultant and Dr Lesley McNair (Clinical Psychologist) will be notified.

## **SETTINGS AND EQUIPMENT**

Facilities at the Department of Psychological Medicine, Gartnavel Royal Hospital will be used in the production of questionnaires and other administrative materials. Data will be analysed using the Statistical Package for the Social Sciences (SPSS) which is also available at the Department of Psychological Medicine. A portable laptop computer will be necessary in order to administer the Stroop measures and access to Superlab software. It is anticipated that some assistance will be required from staff at the Beatson Oncology Centre in order to gain access to appropriate patients, a room for interview purposes, and possibly access to medical records to check what type of treatment patients have received.

## **DATA ANALYSIS**

The information from the questionnaire data will be entered into and analysed by SPSS. Descriptive statistics will be conducted for the purposes of sample description and group differentiation. The main analysis will be paired-samples t-tests and repeated measures Anova to analyse the difference in scores on the main measures (chosen for parametric/nonparametric as appropriate). Additional analysis may also need to be conducted in order to address any further queries that may arise after the initial analysis.

# **PRACTICAL APPLICATIONS**

This study will increase knowledge about the types of pre-sleep thoughts that intrude upon sleep after cancer, and possibly other traumatic events, and will increase awareness about the types of intrusive thoughts that lead to the continuation and maintenance of sleep problems. This will have important implications for early interventions in order to prevent insomnia becoming a long-term problem and consequently decrease the risk of developing other psychological disorders such as anxiety and depression.

#### **TIMESCALES**

The proposed starting date for the project is August 1999. Data collection will take approximately 6 months. Scoring and analysis will take approximately 2 months.

## **ETHICS APPROVAL**

A proposal will be sent to the West Ethics Committee for approval (see appendix 2.6 for letter of approval from the West Ethics Committee).

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## **ADDENDUM**

Due to a slow response to the posters in the Beatson two months following the onset of recruitment, ethical approval was also sought from Ayrshire and Arran Health Board (see appendix 2.7 for letter of approval). Patients were then recruited in Ayrshire and Arran through contact with Consultants. In addition, in-patients were identified through case note review at the Beatson Oncology Centre and Gartnavel Royal Hospital. All Oncology and Haematology Consultants in the Beatson Oncology Centre were also contacted in order to identify additional patients who may be suitable for inclusion.

# 2. MAJOR PROJECT PAPER

The Evolution Of Sleep-Onset Latency Problems:

An Experimental Investigation Of Pre-Sleep Cognition And Attribution In

People With Cancer

Written in accordance with the guidelines for submission to:

Journal of Abnormal Psychology (see Appendix 3.1)

## **ABSTRACT**

This study examined the evolution of insomnia by investigating pre-sleep cognition and attribution, by administering the emotional Stroop task, to two groups of cancer patients who had developed sleep-onset latency (SOL) problems since diagnosis: 15 individuals with cancer 0-3 months from diagnosis (early group); and 18 individuals with cancer 12-18 months from diagnosis (late group). Consistent with the hypothesis, both groups demonstrated attentional bias for cancer-related words but only the late group demonstrated attentional bias for sleep-related words. High levels of pre-sleep cognitive arousal was evident in both groups despite lower levels of psychological distress in the late group. Findings were discussed within the context of current literature and implications for future research was proposed.

#### INTRODUCTION

## Cognitive Factors in Sleep

Research into the aetiology of insomnia has begun to investigate pre-sleep mental and physiological arousal. Evans (1977) was amongst the first to recognise that people complain of mental alertness in bed more than physiological arousal. Nicassio, Debra, Mendlowitz, Fussell, and Petras (1985) developed the Pre-Sleep Arousal Scale (PSAS) and administered it to good and poor sleepers to measure somatic (i.e. physical) and cognitive (i.e. mental) aspects of pre-sleep arousal. This study found that cognitive arousal was more highly correlated with sleep-onset latency (SOL) difficulties than somatic arousal. Although the PSAS correlated with measures of anxiety and depression, it correlated more with measures of sleep disturbance.

Studies which have induced sleep disturbance by manipulating cognitive intrusions in the pre-sleep period (e.g. Gross and Borkovec, 1982) has provided further evidence regarding the importance of cognitive arousal in insomnia. Coyle and Watts (1991) demonstrated that a high level of worry and rumination were the principal characteristics of insomnia, and Nicassio et al. (1985) found that individuals with sleep problems tended to experience more negative thoughts in the pre-sleep period than good sleepers. A recent theoretical review has also suggested that is not the thoughts per se that are untypical but the meaning individuals attribute to them (Espie and Wicklow, 2000).

Research has proposed that the uncontrollable thoughts associated with insomnia are actually centred on the problems they are having with their sleep. Borkovec (1982) for example, found that people with insomnia report a greater number of intrusive thoughts about their sleep. A recent study by Wicklow and Espie (2000) investigated the nature and content of pre-sleep thoughts of insomniacs according to the three systems model of arousal

based on cognitive and somatic arousal, and environmental stimulation (Espie, 1991). Although problem solving was evident in the pre-sleep period, thoughts about sleep itself, for example thinking about past experiences of sleep, was the most commonly reported by insomniacs.

Ansfield, Wegner, and Bowser (1996) explored the effects of different sleep-onset instructions on sleep-onset latency of normal sleepers under either a high or low mental load. There was evidence of paradoxical wakefulness for those participants attempting to fall asleep quickly under a high mental load. This finding was related to Wegner's (1994) theory of a self-loading system where the thwarted desire for mental control becomes the source of mental incapacitation that produces the opposite desired state of mind. They hypothesised that failure to fall asleep on a few occasions could occur when sleep is attempted under transitory mental loads, such as a time of stress. Eventually an individual's pre-sleep thoughts about the inability to sleep under these conditions could come to constitute a chronic and debilitating mental load which, when combined with the continuing and long-frustrated desire to fall asleep, could lead to chronic insomnia.

## Cancer and Sleep

Many studies have reported a high incidence of sleep disturbance in cancer populations (e.g. Derogatis, Feldstein and Morrow, 1979). A recent study by Engstrom, Strohl, Lewandowski, and Stephanek (1999) for example, investigated sleep patterns in breast and lung cancer patients and found that 44% of patients reported difficulties with their sleep. Miaskowski and Lee (2000) used wrist actigraphy and found that oncology patients receiving radiation therapy obtained a mean sleep efficiency index of 70.7%. The cause of sleep disturbance in cancer is often attributed to the side effects of treatment or

medical factors related to the illness, such as pain, with little emphasis on psychological variables (e.g., Jacobsen et al., 1999).

However, the insomnia literature suggests that cognitive arousal, not physical symptoms, may be the primary contributing factor in the development of insomnia in medical conditions. A recent study by Smith, Perlis, Smith, Giles and Carmody (2000) studied pre-sleep arousal in chronic pain patients and found that pre-sleep cognitive arousal, rather than pain severity, was the primary predictor of sleep quality. Tjemsland, Soreide, and Malt (1998) also investigated post-traumatic stress symptoms (PTSD) in breast cancer patients and found that one third of patients continued to have trouble falling asleep at one year since surgery, compared to half at six weeks, because thoughts or images about the illness kept coming into their minds as they attempted to fall asleep.

Insomnia can affect quality of life as it often results in subsequent fatigue and irritability (e.g. Nicholi 1978), and is postulated to be a risk factor for the development of anxiety and depression (e.g. Ford, Lewis, and Fallowfield, 1995). Sleep has also been associated with tissue restoration (Oswald, 1980), pain tolerance (Chuman, 1983), and the immune system (Moldofsky et al., 1986). Owen et al., (1999) highlighted that sleep disturbance in cancer patients resulted in more daytime dysfunction than in healthy controls. As indicated by Pressman et al. (1997), sleep disruption may affect not only mental status and cognitive functioning but also the course, treatment, and recovery from medical disorders. Consequently, the investigation of sleep disturbance in cancer patients would have particular benefits for this population group. In addition, due to the high incidence of sleep problems associated with cancer, investigation of sleep disturbance following diagnosis may be a useful model for assessing pre-sleep cognition and attribution in the development of insomnia.

### Attentional Bias

The cognitive model assumes that attribution plays a vital role in causation and maintenance of psychological distress. Central to the cognitive model of psychopathology is the belief that individuals with emotional disorders have a preoccupation with personally threatening stimuli in their environment due to an information processing bias (Williams, 1996). This cyclic escalation of emotional distress therefore has parallels with the studies outlined above into the development of insomnia. Annsfield et al. (1996) for example, proposed that insomnia is due to biases in attention towards past experiences of the failure to sleep. The theory of information processing bias therefore has particular implications for the study of sleep disorders, whereby attention is drawn to stimuli that remind the individual of past failures and consequences of the inability to fall asleep.

Two broad strategies have generally been employed to study cognition. One method investigates thought content through interviews and questionnaires and the second method has involved application of cognitive psychology methods (McNally, Kaspi, Riemann, and Zetlin, 1990). Questionnaire and interview methods are restricted to conscious cognition, introspection, and are completed retrospectively. This has consequently led to an increase in experimental studies based on cognitive psychology methods. One of the main methodologies has been an emotional analogue of the Stroop task (Stroop, 1935) which has been described as the hallmark measure of attention (McLeod and Hagan, 1991).

The emotional Stroop task has been used to assess cognitive bias in a wide range of clinical conditions such as PTSD (McNally et al., 1990) and agoraphobia (Hayward, Ahmad and Wardle, 1994). It has also been used recently to assess attentional bias in medical conditions such as chronic pain (Pincus, Fraser and Pearces 1998) and patterns of processing selectivity and subsequent emotional response to a colonoscopy (McLeod et al.,

1991). The emotional Stroop test could therefore have important implications for the study of cognitive factors in the evolution of sleep disorders by investigating attentional bias for sleep.

Based on the above literature, there may be a difference in attentional bias for those individuals who have recently developed normative, transient sleep disturbance after a life event as opposed to individuals who have gone on to develop long-term sleep onset difficulties. If the above hypothesis is correct, then individuals who have had long-term sleep problems following diagnosis of cancer would be more likely to attend to sleep words on the Stroop task as they would attribute more meaning to their sleep difficulties than those with sleep disturbance who have recently been diagnosed.

#### **AIM**

The purpose of this study therefore, is to assess the role of pre-sleep cognition and attribution, by using the emotional Stroop task and questionnaire measures, in people with cancer who have developed sleep onset difficulties. This study aims to explore the hypothesis that long-term insomnia is due to biases in attention towards past experiences of the failure to sleep by investigating the development of sleep problems following diagnosis. Pre-sleep cognition and attribution will be investigated by assessing SOL problems in two separate cancer groups based on Tjemsland et al.'s (1998) study: 0-12 weeks after diagnosis (early group); and 12-18 months after diagnosis (late group). It was anticipated that these two groups would allow for the comparison of pre-sleep cognition and attribution in the early and later stages of the development of insomnia. The most suitable type of study to test the hypothesis would have been a prospective study. However, due to time constraints, together with the fact that this is a preliminary test of a hypothesis, this study was cross-sectional.

## **HYPOTHESES**

- 1. There will be no difference in overall level of pre-sleep mental arousal between the two groups;
- 2. Both groups will have higher levels of pre-sleep mental arousal than somatic arousal;
- 3. The early group will attend more to cancer/illness related words and the late group attend more to sleep/insomnia related words;
- 4. There will be a higher incidence of pre-sleep thoughts relating to sleep in the late group;
- 5. There will be a higher incidence of pre-sleep thoughts relating to cancer/illness in the early group.

## **METHOD**

# Design

The design was a 2 X 3 factorial with one between subjects factor (group) and one within subjects factor (word type).

## **SUBJECTS**

Volunteers were recruited from four hospitals in the West of Scotland. The main method of recruitment for out-patients was through leaflets advertising for people who had developed sleep problems since a cancer diagnosis. Patients interested in the study completed the leaflets which were then collected on a weekly basis from the hospital. Case notes were also examined to locate potential in-patients who were then approached about participation in the study while on the ward. There were a number of exclusion and inclusion criteria for both groups:

## Common Inclusion Criteria

- 1. Aged 16-65 years;
- 2. Significant difficulty getting to sleep, i.e. a minimum SOL of 30 minutes, 4 times per week (International Classification of Sleep Disorders, 1997).

### Common Exclusion Criteria

- 1. History of prior sleep problems;
- 2. Active psychological or drug interventions for their sleep problems;
- 3. Evidence of night wakening without any difficulty falling asleep;
- 4. Colour blindness as this would impact on Stroop performance.

# Additional Inclusion Criteria for the Early Group

1. Recent diagnosis of cancer (0-12 weeks).

# Additional Inclusion Criteria for the Late Group

- 1. Cancer diagnosis 12-18 months previously;
- 2. Having had SOL problems since diagnosis.

Due to the fact that this study was a preliminary test of a hypothesis, there was no direct comparison study from which to conduct a power calculation. The best available study which included the Stroop that would be sensitive enough to detect differences on a repeated measure analysis of variance was a study by McNally et al. (1994). This paper used the Stroop to investigate the differential processing of threatening information in people with conditioned anxiety. Using data from this study as the best estimate, a minimum of 21 subjects per group would be required to detect significant differences at

p<0.01, or 11 subjects per group at p<0.05, on a repeated measures analysis of variance with 0.8 power (1-tailed).

A total of 141 patients were screened for the study, 33 of which were suitable for inclusion. This consisted of 15 patients in the late group and 18 in the early group. 104 patients were excluded, as they did not meet inclusion criteria for length of diagnosis; 2 patients were too ill to interview; 1 had sleep problems prior to diagnosis; and 1 had a brain tumour. The mean length since diagnosis for the early group was 2.0 months and 14.3 months for the late group. The mean age for the early group was 46.7 and 48.0 for the late group. An independent samples t-test confirmed that there was no significant difference between the mean age for early and late group (t = 0.39, p = 0.7). As can be seen from Table 1. breast, ovarian, and acute lymphoblastic leukaemia (ALL) were the main cancer types included in this study and there was only a 5% difference in the number of patients who were receiving radiotherapy and chemotherapy in the two groups.

#### **INSERT TABLE 1. HERE**

## **MEASURES**

When patients were identified from the study, either through completed information leaflets or case note review, they were contacted by telephone or on the ward to identify if they met inclusion criteria for the study. Information was also obtained regarding cancer type, medication and treatments received by examination of case notes and interview with patients. An appointment was then arranged with suitable subjects to complete the measures for the study. The Stroop was the primary comparison measure and additional measures were included to assess pre-sleep thoughts, psychological distress, PTSD symptomatology, and thought control strategies in the two groups.

# 1. ATTENTIONAL BIAS - Computerised Emotional Stroop

# Stimuli & Apparatus

This test was administered to assess for attentional bias for threat related material. Twenty cancer and twenty sleep related words were included in this measure together with 40 matched neutral words. The sleep and cancer words were derived from typed transcripts from Wicklow and Espie's (2000) study investigating pre-sleep thoughts in insomnia, and an ongoing research study into the thoughts, beliefs, and interpretations of cancer patients (White, personal communication). The neutral words were taken from a thesaurus and matched to target words in terms of syllable and word length and also frequency of occurrence in the English language.

A practice trial of 20 words naming the colours of the words one, two, three, four, and five (McNally et al., 1994) was presented at each administration (see appendix 2.1). The 80 target words were then randomly presented in each of the four colours: blue; yellow; green; and red. The words were presented with the restriction that the same word type or colour would not appear twice in succession (McNally et al., 1990).

A Viglen Dossier 486 laptop computer was used to present the words in a random order to the subjects. Superlab software (Credus Corporation, 1997) was used to present the words and a four button colour-coded response box (red, green, blue and yellow) (Credus Corporation, 1997) was used to record the response latency (in milliseconds) for each word presented.

## 2. ADDITIONAL COMPARISON MEASURES

#### Pre-Sleep Arousal Scale (PSAS) (Nicassio et al., 1985)

This self-administered questionnaire includes 8 cognitive and 8 somatic statements relating to manifestations of arousal that people may experience in the pre-sleep period.

Satisfactory internal consistency has been demonstrated for both the somatic and cognitive subscales (r = 0.81 and r = 0.76 respectively). The PSAS also has acceptable face and construct validity (Nicasso et al, 1985). Subjects were asked to rate on a five point scale (not at all to extremely) to what degree they experienced somatic and cognitive arousal. This measure was administered to assess for any differences in cognitive and somatic arousal in the two groups.

# **Sleep-Onset Thought Scale (SOTS)**

This questionnaire was developed for the study to retrospectively assess the frequency and intrusiveness of insomnia and cancer related cognitions during the sleep-onset period. There were two versions of this measure: one for the early group; and one for the late group (see appendix 2.2 and 2.3). Both versions included the same 8 insomnia and 8 cancer related thoughts but the tense was changed for the late group. Patients were asked to indicate how much they felt each thought intruded upon their ability to fall asleep by placing a mark on a 10 point visual analogue scale.

The thoughts identified for the sleep related cogntions were derived from the two main factors identified from the analysis of Wicklow and Espie's (2000) study. These two factors were 'sleep and its consequences' and 'cognitive rehearsal/problem solving'. Cancer related thoughts were derived from psychosocial oncology studies and from personal communications with Clinical Psychologists working within cancer populations. Three postgraduate psychologists were asked to classify the items according to cancer and sleep categories before they were included in the scale which resulted in 100% agreement.

## Impact of Events Scale (IES) (Horowitz et al., 1979)

This standardised questionnaire included 7 questions relating to intrusive symptomatology and 8 questions relating to avoidance symptomatology associated with

PTSD. Horowitz et al (1979) reported satisfactory split half and test re-test reliability for this measure. Internal consistency of the subscales was also high for intrusion and avoidance (r = 0.78 and r = 0.82 respectively). Patients were asked to respond on a four point scale (not at all to often) to the 15 items. It was administered to assess differences in avoidance and intrusive symptoms in the two groups as the hypothesis suggests that sleep problems in the late group should not be related to high avoidance or intrusive symptoms.

## General Health Questionnaire 12 (GHQ12) (Goldberg and Williams, 1978)

This standardised measure aims to assess general levels of psychological distress. It includes 12 items based on a four point scale (better than usual to much worse than usual). The GHQ-12 is a very reliable, valid and sensitive measure often used in research studies (Goldberg and Williams, 1978). It was included to assess levels of psychopathology in the two groups as the hypothesis indicates that sleep problems in the late group should not be the result of high levels of psychological distress.

# Thought Control Questionnaire (TCQ) (Wells and Davis, 1994)

This questionnaire measures individual differences in thought control strategies for unwanted intrusive thoughts. It includes 30 items and patients were asked to respond on a four point scale (never to almost always). Test re-test reliability (r = 0.83) and internal consistency has been demonstrated for this measure (Wells and Davies, 1994). It was administered to determine whether the two groups used different thought control strategies as this may impact upon intrusive pre-sleep thoughts. Differences in thought control strategies have also been found to relate to measures of stress vulnerability.

#### **PROCEDURE**

Subjects were interviewed in a confidential environment in the hospital. They were asked to complete the GHQ12, PSAS, TCQ, IES, and the SOTS under the direction of the interviewer which took approximately 30 minutes. Subjects were then told that they were going to be given a computerised measure. They were given the colour-coded response box and the following instructions appeared on the screen:

In this test you will see a series of words presented one at a time on the computer screen. The words will be randomly presented in the colours RED, GREEN, BLUE or YELLOW. The aim is to focus on the colour of the word, not the meaning of the word. There are four colour coded response buttons for you to respond to the colour of the word. The aim is to press the correct colour coded response button as quickly as you can. A practice trial of twenty words will be presented first. Please press any key to continue.

They were given a practice trial of 20 words naming the colours of the words one, two, three, four, and five to ensure that they were not colour blind and understood the task. The 80 words were then randomly presented (McNally et al., 1990) in each of the four colours. Although this measure was not always administered in the same location, administration was consistent to ensure that the task was completed in a standardised manner. Each subject was asked to place their four fingers of their dominant hand over the four colour-coded response buttons. The computer was always on a table at eye level for the subject, and the environment was as free from distracters as possible.

#### RESULTS

## **Psychological Distress**

As can be seen in Table 2. there was a significant difference between the two groups on the GHQ with the early group having higher levels of psychological distress. Independent samples t-tests for IES scores demonstrated that the early group had significantly higher levels of avoidance but not intrusive symptoms relating to their illness than the late group. Total IES scores were also significantly higher in the early group.

# Pre-Sleep Arousal

Results on the PSAS, which can also be seen in Table 2., indicated that the two groups did not differ significantly on pre-sleep cognitive or somatic arousal. However, an independent samples t-test indicted that there was a significant difference between overall cognitive and somatic scores (t = -5.6, p = 0.01) for both groups. The mean for pre-sleep somatic arousal was significantly lower (mean = 9.1, s.d. = 5.6) than cognitive arousal (mean = 17.0, s.d. = 6.9). Cognitive arousal therefore was significantly higher than somatic arousal for both groups in the pre-sleep period and despite the differences in GHQ and IES scores, with the exception of intrusive symptoms, both groups experienced similar levels of pre-sleep cognitive arousal which confirmed hypothesis one and two.

#### **INSERT TABLE 2. HERE**

## **Attentional Bias**

Errors and outliers (i.e. latencies <300 or >2000) were not included in the analysis (NcNally et al., 1994). The means and standard deviations for the colour-naming latencies can be seen in Table 2. Response latencies were submitted to a group (early or late) x word type (neutral, cancer, or sleep) repeated measures analysis of variance. There was a significant effect for word type, F (2, 62) = 16.7, p < 0.001, and group x word type

interaction, F (2, 62) = 11.0, p = 0.001. There was no significant main effect for group, F (1, 31) = 0.4, p = 0.55. As can be seen in Table 2. the test for simple main effects of word type indicated that the groups did not differ significantly in their response to neutral or cancer words but the late group took significantly longer to respond to sleep words than the early group.

In order to provide a measure of colour-naming interference due to threat, an interference index score was calculated by subtracting the time to complete the neutral words from time to complete target words (Williams & Broadbent, 1986) which is plotted in Figure 1. Interference scores were submitted to an independent samples t-test. This indicated that there was no significant difference between the two groups for the cancer word interference index (t = 0.91, p = 0.37) but there was a significant difference between the two groups for the sleep word interference index (t = -2.44, p = 0.02). This illustrates more clearly that both groups showed interference for cancer words relative to neutral words but only the late group exhibited Stroop interference for sleep words which confirmed hypothesis three.

#### **INSERT FIGURE 1. HERE**

The above findings therefore supported the main hypothesis for attentional bias. However, in order to determine whether this effect could be accounted for by the higher IES scores in the early group, mean reaction time for word type was analysed according to low (0 - 8), medium (9 - 19) and high (+20) IES scores (Pelcovitz et al, 1998). Interference index scores were calculated according to word type and can be seen in Figure 2. These scores were submitted to a one-way ANOVA which indicated that there was no difference between the groups for the cancer word interference index, F (2,32) = 2.2, p = 0.13, but there was a difference between the early and the late group for the sleep word

interference index, F = 5.9, p = 0.01. Bonferroni post hoc tests (Kinnear and Gray, 1999) confirmed there was not a significant difference between the three groups for the cancer word interference index. There was however, a significant difference between the low and medium IES group (mean difference = 222.4, p = 0.01), and the low and high IES group (mean difference = 210.2, p = 0.01) for the sleep word interference index. Taken together these results show that the low IES group differed significantly from the medium and high IES group for sleep word interference scores but not cancer word interference scores. There was no difference between the medium and high IES score for either sleep or cancer word interference index scores.

## **INSERT FIGURE 2. HERE**

# Pre-Sleep Cognition (SOTS)

Discussion with patients while completing the SOTS questionnaire highlighted that 3 of the items originally included as sleep items were ambiguous and could not accurately be defined as sleep items. Item no. 13 for example, 'think about work or social events' was ambiguous as they were no longer able to engage in these activities due to cancer. As a consequence, only 5 of the original items in this measure could be validly categorised as sleep items, which specifically refer to thinking about sleep while in bed. The 3 ambiguous items were therefore removed from the analysis (see appendix 3.3). Mann-Whitney Tests were conducted as the distribution was not normal. As can be seen in Table 3. these results indicated that there was no difference between the mean ranks for the two groups for retrospective rating of cancer or sleep related thoughts on the VAS experienced while attempting to fall asleep.

## **INSERT TABLE 3. HERE**

In order to clarify whether sleep or cancer related thoughts were rated as most significant for the early or late group, patients were also asked to rank order the three out of the sixteen items which they felt intruded most upon their ability to fall asleep. For the purposes of analysis, value labels were attached to the ranking of cancer and sleep items according to the following categories: rank 1 = 3; rank 2 = 2; rank 3 = 1. This therefore, produced a frequency ranked sleep and cancer item total score according to group (i.e. early or late). Ambiguous items were excluded from the analysis. As can be seen in Table 3. the late group ranked sleep items more frequently than the early group although there was no significant difference in the two groups for frequency ranking of cancer items. (See appendix 3.4 for mean rank results on SOTS including the three ambiguous items).

The three pre-sleep thoughts with the highest frequency ratings for the early group were:

- 1. Item 1. (Cancer) 'Think about what the future might hold'
- 2. Item. 5. (Cancer) 'Think about whether you will get better'
- 3. Item 10. (Cancer) 'Think about the consequences cancer is having on your life'

The three pre-sleep thoughts with the highest frequency rating for the late group were:

- 1. Item 3. (Sleep) 'Think about how difficult you are finding it to fall asleep'
- 2. Item 10. (Cancer) 'Think about the consequences cancer is having on your life'
- 3. Item 2. (Sleep) 'Think about previous nights when you could not get to sleep'

These results show that the early group rated three cancer items as most relevant whereas the late group ranked two sleep and one cancer item as most relevant. This therefore might suggest that the late group ranked pre-sleep thoughts as more intrusive

upon their ability to fall asleep than the early group. The ranking results on the SOTS therefore appear to support hypothesis four and five although they were not supported by results on the VAS.

# **Thought Control Strategies**

Independent samples t-tests for the thought control strategies used by both groups from the TQC recorded no significant differences between groups for any of the types of thought control strategies used to control unwanted intrusive thoughts (See appendix 3.5 for graph of TCQ results). Distraction, re-appraisal, and social control were the most commonly reported strategies in both groups.

#### **Qualitative Data**

Patients were also asked to state any other factors that they felt were intruding upon their ability to sleep. Fourteen patients (42%) of the total sample took the opportunity to report additional factors that they felt contributed to their disturbed sleep pattern which included the following: night sweats (21%); pain (6%); onset of chemotherapy (6%); fear for the future (6%); and noise (1%). All of the patients who identified night sweats as a problem were receiving tamoxifen which was independent of group.

#### **DISCUSSION**

In accordance with the hypotheses, the late group, relative to the early group, exhibited greater interference for sleep-related words on the Stroop task but not for cancer-related or neutral words. Reaction time for neutral words was similar for both groups and although both groups demonstrated interference for cancer-related words relative to neutral words, there was no significant difference between the two groups in attentional bias for cancer-related words.

Both groups had higher levels of pre-sleep cognitive arousal than somatic arousal on the PSAS which was also consistent with the hypotheses. Levels of psychological distress as measured by the GHQ, and overall PTSD symptomatology measured by the IES, was higher in the early group. This demonstrated that sleep latency problems, especially pre-sleep cognitive arousal, persisted in the late group despite lower levels of psychological distress. However, intrusion scores on the IES were similar in both groups and it could be argued that this accounted for the high levels of pre-sleep cognitive arousal in the late group. Results on the SOTS for retrospective rating of pre-sleep thoughts does indicate that there was no difference between the two groups for pre-sleep thoughts relating to sleep or cancer. Nevertheless, ranking of the three most intrusive pre-sleep thoughts suggests that the late group regarded sleep items as more intrusive upon the ability to fall asleep than the early group despite the high levels of intrusive symptoms relating to cancer in both groups.

In addition, despite high levels of intrusive symptoms, only the late group exhibited attentional bias towards sleep-related words on the Stroop task. Analysis of results on the Stroop task according to IES scores indicated that although interference for cancer-related words was high relative to neutral words, this was not a function of high PTSD symptomatology as there was no significant difference between interference scores for cancer-related words according to low, medium, or high IES scores. Interference for sleep-related words however, was higher in the low IES grouping which suggests that attentional bias for sleep-related words was more prevalent in individuals with low PTSD symptomatology.

The levels of unwanted intrusive thoughts regarding sleep or cancer were not a function of different thought control strategies, as there was no difference between the two groups on any of the sub-scale scores on the TCQ. The qualitative data subjects provided

also indicated that their sleep problems were not a result of physical symptoms which provided further support for the hypothesis that cognitive arousal, as opposed to somatic symptoms, was the most likely to impact on sleep latency. Night sweats were the only physical symptom of note that some patients felt impacted upon their ability to fall asleep. This appeared to be due to the side effects of tamoxifen as only individuals receiving this drug indicated that night sweats were contributing to their sleep disturbance. However, this was only a small percentage of the sample. Pain was only considered to be a contributing factor in six per cent of the total sample. Individuals who reported physical factors also rated pre-sleep cognitive arousal on the PSAS as the most intrusive factor upon their ability to fall asleep.

Taken together, the findings of this study are therefore consistent with the insomnia literature (e.g., Nicasso et al., 1985) which suggests that cognitive arousal, as opposed to somatic arousal, is the main contributing factor to sleep disturbance. This is in contrast to some studies of sleep disturbance in cancer populations (e.g., Monroe and Potter, 1996) which suggests that sleep disturbance can be attributed to physical or medical factors associated with cancer. Sleep difficulties in this population group have also been attributed to psychological factors such as depression and anxiety (e.g., Beszterczey and Lipowski, 1977) but this study has highlighted that sleep problems appear to persist despite low levels of psychological distress. In accordance with the findings of studies such as Smith et al. (2000), it would appear that sleep problems in individuals with cancer, according to the findings of this study, could be related to high levels of pre-sleep cognitive arousal and not illness variables.

Results on the Stroop also indicated that individuals in the late group demonstrated attentional bias and pre-sleep cognitive arousal towards sleep. The findings of this study

therefore appear to support Ansfield et al.'s (1996) theory and the findings from Wicklow and Espie's (2000) study which proposes that individuals who have developed long-term sleep problems, as opposed to transient sleep disturbance following a life event, demonstrate pre-sleep cognition and attribution towards past failures regarding the inability to fall asleep. Although there was not sufficient power in this study to analyse the effects of PTSD symptomatology on attentional bias, the results suggested that pre-sleep cognition and attribution towards past failures regarding the inability to fall asleep may only be evident in those individuals who have low levels of PTSD symptomatology. However, the late group had high levels of intrusive thoughts about cancer but continued to demonstrate attentional bias towards sleep. Furthermore, irrespective of IES scores, only the late group indicated on the SOTS that pre-sleep thoughts about the difficulties they were having with their sleep were the most intrusive upon sleep in the pre-sleep period.

This study therefore provides important information regarding sleep disturbance within cancer populations. Insomnia in this population has often been ignored as it was thought to be related to relatively uncontrollable medical variables such as pain or the side effects of treatment. Although this may be the case in a proportion of patients, it would appear that high levels of pre-sleep cognitive arousal is the primary factor associated with sleep disturbance. The findings also appeared to suggest that insomnia may be perpetuated by pre-sleep cognition and attribution towards past experiences of the failure to fall asleep following a stressful life events (see Figure 3). It is possible therefore, that basic sleep hygiene in the early stages of sleep disturbance following diagnosis could prevent insomnia becoming a long-term problem and could also prevent the development of further psychological disturbance associated with insomnia such as depression or anxiety.

#### **INSERT FIGURE 3. HERE**

Although this study was a preliminary test of a hypothesis, it has provided evidence for the valuable role of cognitive psychology methods, such as the use of the Stroop, to measure variables related to insomnia. It is anticipated that a larger prospective study could provide further support for the role of cognition and attribution with the use of the Stroop and associated questionnaire measures. The SOTS developed for this study was limited due to the retrospective nature of questionnaire measures. Furthermore, although the sleep items included in this measure would have been suitable for an insomnia group in the general population, it would have been beneficial to pilot the sleep questions in a population of cancer patients with insomnia prior to use within the study as ambiguous items could have been excluded from the questionnaire.

Future studies could further develop a pre-sleep thought questionnaire based on the findings from insomnia studies, such as Wicklow and Espie (2000), which would provide a more meaningful measure of pre-sleep thoughts in insomnia populations. More specifically, this questionnaire could be based on the three systems model of arousal which included cognitive, somatic, and environmental stimulation (Espie, 1991). It may also be possible for studies investigating the nature of pre-sleep thoughts to use additional measures of pre-sleep cognition, such as a voice activated recorder or checklist, in the earlier and later stages of insomnia. It would also be beneficial for future studies to obtain diary and objective measures of sleep such as wrist actigraphy to obtain accurate measures of sleep latency difficulties as questionnaire measures and interviews are often inaccurate due to subjective and retrospective analysis. Patients with insomnia tend to overestimate how long it takes them to fall asleep when compared with objective measures (e.g. Edinger and Fins, 1995) and consequently an objective measure could ensure more accurate recording of sleep latency.

The current study was also limited by a number of additional factors. It was anticipated that subjects in the early and late group would be matched according to age, sex and cancer type to reduce variation between the two groups. However, due to recruitment difficulties and time constraints it was not possible to conduct a matched pair design. Consequently, a prospective or matched pair design could address this issue. A number of cancer types were also included and future research should aim to include matched groups to identify variables specific to each cancer type.

Due to the recruitment difficulties and illness variables, patients also had to be seen in different hospital sites. The Stroop should ideally be administered in the same standardised manner and location (McNally et al., 1990) for each administration to ensure that environmental variables do not contribute to the findings. Any further studies should aim to use the Stroop in the same environment to ensure external factors did not contribute to the findings on the Stroop in this study.

In summary, this study has found that individuals with cancer who have developed long-term sleep disturbance differ from those with transient sleep problems following diagnosis in terms of pre-sleep cognition and attribution. It provides support for the theory that insomnia may be perpetuated by pre-sleep cognition and attribution towards past failures regarding the inability to fall asleep (e.g., Wicklow and Espie, 2000). Although illness and treatment variables may contribute to sleep difficulties in individuals with cancer, this study suggests that pre-sleep cognitive arousal is the main contributing factor to sleep disturbance within this, and possibly other, population groups. It is hoped that further investigation of pre-sleep cognition and attribution may provide valuable information regarding the evolution of sleep-onset latency problems and therefore the development of appropriate interventions for the prevention and management of insomnia.

FIGURE 1. Mean Stroop Interference Scores As A Function Of Word Type by Group

(bars indicate standard error of the mean)

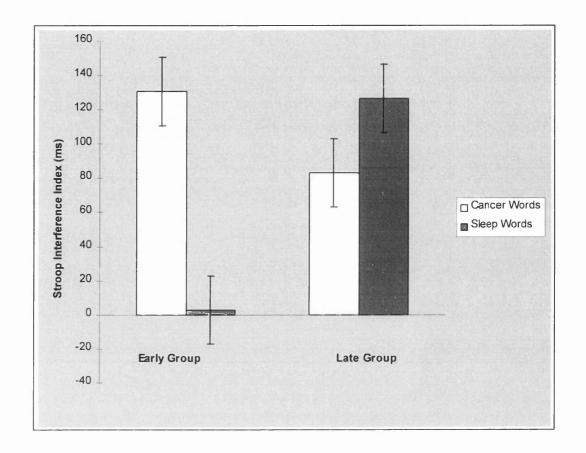


Figure 2. Interference Index according to IES score for Word Type

(bars represent standard error of the mean)

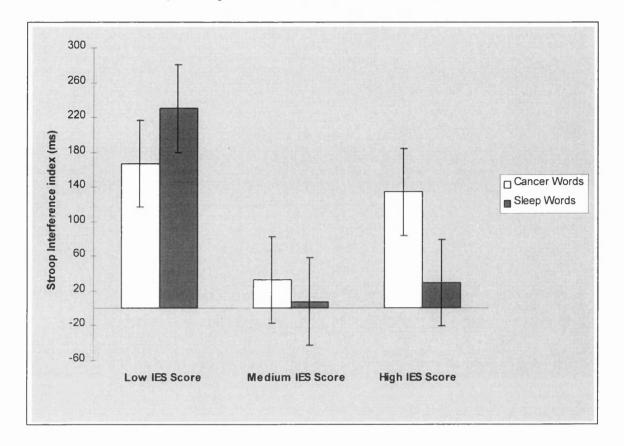


Figure 3. Proposed Evolution of SOL Difficulties Following Stressful Life Events

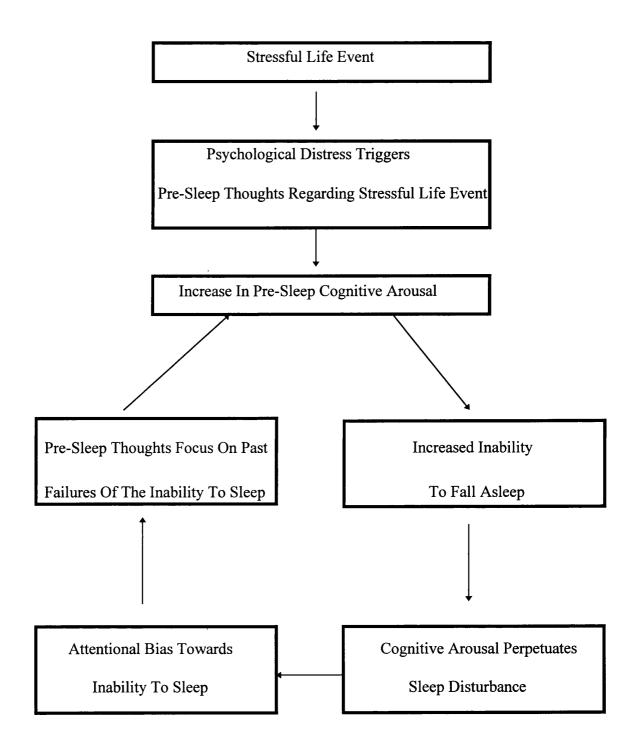


Table 1. Characteristic Of Sample

|                       | Early Group        | Late Group         |  |
|-----------------------|--------------------|--------------------|--|
|                       | (% of total)       | (% of total)       |  |
| Sex (Male/Female)     | 6 (33%) / 12 (67%) | 4 (27%) / 11 (73%) |  |
| Breast Cancer         | 9 (50%)            | 8 (53%)            |  |
| Ovarian               | 3 (17%)            | 1 (7%)             |  |
| ALL                   | 2 (11%)            | 2 (13%)            |  |
| Other Cancer Type*    | 4 (22%)            | 4 (27%)            |  |
| Receiving Tamoxifen   | 3 (18%)            | 3 (20%)            |  |
| Received Radiotherapy | 5 (28%)            | 5 (33%)            |  |
| Received Chemotherapy | 14 (78%)           | 11 (73%)           |  |
|                       |                    |                    |  |

n = 33; \*Please refer to appendix 3.2 for detailed list of all cancer types included in study.

Table 2. Results on Main Measures

|                      | Early Group    | Late Group     | Between Groups  |
|----------------------|----------------|----------------|-----------------|
|                      | Mean (SD)      | Mean (SD)      | Analysis        |
| GHQ                  | 6.2 (3.2)      | 3.2 (3.7)      | t = 2.47        |
|                      |                |                | p = 0.02        |
| IES Avoidance        | 15.3 (9.7)     | 8.7 (7.6)      | t = 2.20        |
|                      |                |                | p = 0.04        |
| IES Intrusion        | 15.2 (9.6)     | 9.5 (6.9)      | t = 1.92        |
|                      |                |                | p = 0.06        |
| IES Total            | 29.4 (17.3)    | 18.2 (13.5)    | t = 2.04        |
|                      |                |                | p = 0.05        |
| PSAS Cognitive Score | 16.9 (6.7)     | 17.1 (7.3)     | t = -0.072      |
|                      |                |                | p = 0.76        |
| PSAS Somatic Score   | 9.7 (6.0)      | 8.5 (5.2)      | t = -0.61       |
|                      |                |                | p = 0.55        |
| PSAS Total Score     | 26.6 (9.9)     | 25.6 (9.4)     | t = 0.03        |
|                      |                |                | p = 0.94        |
| Stroop Neutral Word  | 964.5 (133.8)  | 961.9 (112.7)  | F(1,32) = 0.004 |
| Reaction Time        |                |                | p = 0.95        |
| Stroop Cancer Word   | 1093.5 (159.9) | 1049.5 (135.7) | F(1,32) = 0.71  |
| Reaction Time        |                |                | p = 0.41        |
| Stroop Sleep Word    | 964.6 (11.4)   | 1089.9 (177.5) | F(1,32) = 6.12  |
| Reaction Time        |                |                | p = 0.02        |

Table 3. Mean Rank Scores for SOTS by VAS and Top Three Ranking of Items (excluding 3 ambiguous items)

| <u> </u>                    | Early Group | Late Group | Mann-Whitney |
|-----------------------------|-------------|------------|--------------|
|                             | Mean Rank   | Mean Rank  | Test         |
| VAS Eight Cancer Item Score | 18.3        | 16.6       | U = 130.5    |
|                             |             |            | p = 0.64     |
| VAS Five Sleep Item Score   | 15.6        | 19.7       | U = 109.5    |
|                             |             |            | p = 0.23     |
| Top Three Rankings for      | 19.7        | 13.8       | U = 86.5     |
| Cancer Items                |             |            | p = 0.08     |
| Top Three Rankings for      | 13.8        | 20.9       | U = 77.0     |
| Sleep Items                 |             |            | p = 0.03     |

n = 33

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# 4. SMALL SCALE SERVICE EVALUATION PROJECT

The Effect Of Departmental Changes On Patient Satisfaction:

Comparison With Previous Findings

Written in accordance with the guidelines for submission to: Health Bulletin (Appendix 4.1) **ABSTRACT** 

**Objective:** To assess whether departmental changes implemented after a satisfaction survey of Clinical Psychology services in 1995, specifically the introduction of information leaflets, had an effect on patient satisfaction.

**Design**: A postal satisfaction questionnaire was sent to a sample of patients referred to a Clinical Psychology department in 1997. The questionnaire was identical to one devised for a previous satisfaction survey in 1995 and included additional questions relating to the introduction of information leaflets. Overall satisfaction was analysed descriptively and questions relating to the information leaflet was analysed using chi-square.

Setting: Clinical Psychology Department, Lomond Healthcare NHS Trust.

**Subjects:** A random sample of 120 out-patients referred to the Clinical Psychology Department between January and July 1997, matched to the 1995 group for mean age and sex.

Results: The survey elicited a 45% response rate similar to the 1995 study. Overall patient satisfaction in 1995 and 1997 was very high and patients were satisfied with the information leaflet. It appeared to improve patient expectations before first appointment and enhanced the amount and quality of information that referrers were providing to the patients about the service. There was a slight decrease in the perception of some aspects of the service from 1995 such as: number and length of sessions; understanding of formulation; and reduction in the perceived length of benefits after discharge. The applicability of advice provided was highlighted as an area for improvement. Conclusions drawn were interpreted with caution due to the size of the sample.

Conclusions: The survey provided a worthwhile picture of past and current service users' views of the Clinical Psychology department indicating that patients were satisfied with the service provided. Although some limitations with the study were evident, recommendations were made regarding the services offered. It was concluded that satisfaction studies, especially when they are not one-off events, are beneficial. Implications for future research in this area was discussed.

### INTRODUCTION

Since the mid-1970s research on patient satisfaction has grown rapidly <sup>1, 2</sup> and have particular applicability to clinical psychology services.<sup>3</sup> Despite methodological and theoretical difficulties <sup>4, 5</sup> consumer opinion surveys can be used to assess which aspects of the service might be changed in order to enhance client satisfaction.<sup>3</sup> Although many patient satisfaction studies have been conducted, most have surveyed in-patients. Jones and Hodge for example, looked at 14 surveys of patient satisfaction within the mental health field and found that only one study examined users' views of out-patient facilities.<sup>6</sup> In addition, Stallard highlighted that satisfaction surveys are usually one-off events which render comparisons between or within services extremely difficult.<sup>7</sup>

In 1995 a patient satisfaction survey of out-patients was conducted by the Clinical Psychology Department of Lomond Healthcare NHS Trust. The findings of this study indicated that, overall, the patients were satisfied with the service they were receiving. Informing the client about what to expect from seeing a Clinical Psychologist was highlighted as the main area for improvement with 76.5% of respondents receiving either no information of this kind, or not as much as they would have liked. Of those who received some indication of what to expect, general practitioners appeared to be the main providers of information. As a result, two information leaflets were introduced: one for patients which included general information about the nature of clinical psychology assessment and treatment; the second was devised for referrers to inform them about the clinical psychology service. Waiting times and improving communication with patients were also identified as needing improvement. Both of these areas had been addressed as waiting times were reduced and a variety of clinically relevant handouts were introduced to improve communication with patients.

These findings from the 1995 survey were consistent with research done by Watson and Leathem who found that 86.9% of new referrals had not been given any description of possible procedures and that there was a wide range in patient expectations.<sup>8</sup> This is an important issue because patient expectations have been found to correlate with patient satisfaction and non-attendance.<sup>9</sup> There is mounting evidence that an individual's subsequent satisfaction with treatment is related to fulfilment of expectations. As stated by Bergin, if a patient's expectations are 'incongruent with what actually occurs, the client could become dissatisfied and withdraw from therapy' (p.201) indicating that early terminators were those whose expectations were least accurate.<sup>9</sup> A similar study by McGill also suggested that an information pamphlet 'may have a useful role to play in encouraging attendance and improving feelings about working psychologically' (p. 11).<sup>10</sup> In addition to this, a review of information-giving by Ley and Morris suggested that clinician-to-patient oral communication often fails to cover topics that the patients feel are important and therefore leaves the patient feeling dissatisfied. <sup>11</sup>

The use of written material to market psychological services is also becoming increasingly popular because it can raise referrers' awareness of what Clinical Psychologists can offer. <sup>12</sup> Consequently, information leaflets may enhance the amount and quality of information referrers provide to patients and subsequently may encourage attendance and improve perspectives about working psychologically.

This study aimed to assess whether changes introduced since the 1995 satisfaction survey in Lomond Healthcare NHS Trust Clinical Psychology Department, and specifically the introduction of the information leaflets, had influenced patient satisfaction. Consequently the main aims of the study were to assess:

- (i) overall patient satisfaction compared to the results in 1995;
- (ii) areas of the service that patients report as increasing or decreasing patient satisfaction;
- (iii) the extent to which patients report satisfaction with regard to the effect of the information leaflet;
- (iv) if there should be any changes made to the information leaflets or, perhaps, the service in general.

### **METHOD**

The previous study in 1995 selected 228 patients for participation in the study. Those who failed to attend any of their appointments were eliminated. This left a total of 98 who were sent satisfaction questionnaires which were compiled by the Clinical Psychology department. The groups included 50 clients who were still being treated and 48 who had been discharged. The return rate was 64% with 58 of the questionnaires being completed.

Return rates for consumer evaluation studies are typically 50 to 60 per cent.<sup>4</sup> Consequently for this study a random sample of 120 patients referred between January and June 1997 who attended more than one appointment were selected. Twenty clients were randomly selected from each month in this 6 month period, which included 60 discharged and 60 current patients. Their sex distribution was identical to the 1995 sample. The mean age was also calculated (mean age in 1995 was 39.7 and mean age in 1997 was 36.5) to produce a population sample similar to the 1995 survey.

Two patient satisfaction questionnaires were used in the 1997 study, one for current and one for discharged patients. These were the same as the questionnaires in the 1995 survey but with the inclusion of five new questions relating to the information leaflets<sup>13</sup> (see appendix 4.2 & 4.3). The questionnaires were sent by post with a stamped addressed envelope for

return. Anonymous questionnaires were used to prevent any reporting bias. Questionnaires not returned within a month were followed up by post.

Once the questionnaires were returned, the answers to each of the questions in the current study were collated. The results for the current and discharged patients from the 1995 group were compared with the results of the current and discharged patients in the 1997 sample for overall satisfaction. A chi-squared test was used to analyse the data relating to the information leaflet, included only in the 1997 group, using SPSS for windows. Chi-squared tests do not appear for the remaining data related to overall satisfaction because many of the expected frequencies were less than 5. The remaining data relating to overall satisfaction for the 1995 and 1997 groups was therefore analysed descriptively.<sup>14</sup>

### **RESULTS**

Out of the 120 questionnaires that were sent to the 1997 group, 51 questionnaires (45%) were returned which included 26 current and 25 discharged patients.

# Patient Satisfaction - Comparison Between 1995 & 1997

Questions relating to patient satisfaction, with the exclusion of the patient information leaflet, for the two groups (1995 and 1997) were examined according to the following categories:

# (i) Sessions With The Clinical Psychologist

As can be seen from Figure 1., 93% of the 1995, and 85% of the 1997 group rated that the length, number and frequency of sessions with the psychologist was 'about right'. In addition, 84% of patients in 1995 and 80% of patients in 1997 indicated that they had enough time to discuss their problems. 14% of the 1997 group rated the number and length of session as less than they would have liked which was slightly more than 1995 (8%).

#### **INSERT FIGURE 1 HERE**

# (ii) Confidentiality

There was no apparent difference in patients overall perception of confidentiality. 100% of patients in 1997 and 96% of patients in 1995 felt that what they told the psychologist remained private and confidential.

# (iii) Assessment & Advice

As can be seen from Figure 2., there was a slight decrease in the patients understanding of the Clinical Psychologist's explanation of their assessment between the two samples. 50% of patients in 1995 and 52% in 1997 rated that they could use the information given most of the time, suggesting no perceived difference with this aspect of the service.

### **INSERT FIGURE 2 HERE**

# (iv)Completion Of Treatment

The discharged patients in both groups indicated that the treatment ended at the right time (94% in 1995, and 92% in 1997). More patients in 1997 were offered follow-up appointments than in 1995. There was a small number of people in both groups who stopped attending before the completion of treatment, 9 in total. Although this did not provide enough data to assess why people stop attending, the main reason given was that treatment was not helping and external circumstances.

# (v) Overall Helpfulness Of Treatment

91% of the 1995 group and 82% of the 1997 group rated that their treatment was very, or on the whole helpful. There was a slight decrease in patient perception of helpfulness of the treatment in the 1997 group. This was supported by the discharged group's rating of whether any benefits lasted. 100% of the 1995 group and 78% of the 1997 group rated that

benefits did last. The most helpful parts of treatment for both groups can be viewed in Figure 3.

# **INSERT FIGURE 3 HERE**

# (vi) Additional Comments

16 patients in 1995 and 18 patients in the current survey provided additional comments about the psychology service. This qualitative data indicated that 19% of the 1995 sample and 22% of the 1997 sample expressed negative opinions of the service. Of these negative replies most were related to the length of wait before first appointment. The length of wait before first appointment was less in 1997 than in 1995. However there was only a difference of one week in the mean estimate of waiting time before the first appointment for both groups regardless of the actual length of waiting time. However, comments provided suggested that an estimated wait of 8-9 weeks was still regarded as too long.

Only one person from the 1995 sample and 2 from the 1997 sample were negative about the overall service they received. A sample of positive comments from the 1997 group included: 'the service offered has been of great benefit'; 'I am delighted with the continuing support and non-judgemental understanding of the psychologist; and 'I would strongly recommend the service to anyone who needed help'. Most comments were related to the friendliness, understanding, and sympathy of the staff. Overall, the qualitative information appeared to reflect that most patients were happy with the service.

### **INSERT TABLE 1. HERE**

# **The Information Leaflet**

As can be seen in Table 1., most of the 51 individuals in the 1997 group responded to questions relating to the information leaflet. Of these, 39 people (93%) reported that it had

been helpful. Chi-squared analysis confirmed that this was significant above the 0.001 level. 29 people (67%) indicated that it contained enough information about what to expect with chi-square confirming significance above the 0.05 level. 76.5% of individuals in the 1995 group did not know what to expect from seeing a Clinical Psychologist, compared to 33% in 1997, and consequently the information leaflet did appear to improve patient expectations.

The 33% who felt that the leaflet did not contain enough information indicated what other information they would like to have been included (see Figure 4). 88% of discharged patients in 1995 and 77% in 1997 also reported that the result of treatment was what they expected.

### **INSERT FIGURE 4 HERE**

There was some evidence from the 1997 group that referrers were providing some, or all, of the information required about what to expect from seeing a Clinical Psychologist (44% in 1995 and 55% in 1997) and consequently a decrease in the number of referrers who were providing no information ( see Figure 5). As a result, the information leaflets, both for the patients and the referrers, did appear to be beneficial and had some effect on patient expectations.

# **INSERT FIGURE 5 HERE**

### **DISCUSSION**

The results of this study indicated that both the 1995 and 1997 sample were satisfied with the service they were receiving. Moore et al. highlighted that approximately three quarters of clients seen in outpatient settings report being satisfied with Clinical Psychology services, consistent with the above findings. <sup>15</sup>

However, there was evidence of a decrease in the perception of satisfaction with some aspects of the service in 1997 compared to 1995 although the differences were small. The main areas where a decrease was evident were the Clinical Psychologist's explanation of their assessment, the number and length of sessions offered, and the duration of improvement after discharge. Examination of the most helpful aspects of treatment highlighted that patients perceived that there was less time and space to discuss their problems, and that the techniques offered were considered as less helpful. The 1995 study highlighted that the applicability of advice offered was not rated very highly. This was also found in the 1997 group suggesting no perceived change with this aspect of the service. Nevertheless, most patients in 1997, compared to 1995, were satisfied with aspects of the service relating to confidentiality, advice given, sessions, the completion of therapy, and overall helpfulness of treatment. The 1997 sample also rated the Clinical Psychologist's understanding of their difficulties as higher than in the 1995 sample.

The information leaflet sent to patients before their first appointment was regarded as helpful and appeared to improve patient expectations and understanding about coming to see a Clinical Psychologist. In addition, the information leaflets appeared to have a positive effect on referrers as there was a reported increase in satisfaction with the amount and quality of information referrers were providing. It was difficult to determine from the above data whether improving patient expectations had any effect on overall satisfaction because a high level of patient satisfaction was reported in both 1995 and 1997. However, studies have found that patient expectations are the best predictors of patient satisfaction.<sup>16, 17</sup> A high proportion of patients given the information leaflet indicated that the leaflet initially helped enhance expectations about seeing a Clinical Psychologist and in this context can be viewed as improving patient satisfaction.

The main areas that some patients would have liked more information about in the leaflets were: the difference between a Clinical Psychologist and Psychiatrist; the type of treatment available; what a Clinical Psychologist does; and length of appointment. However, anecdotal evidence suggests that patients (and occasionally referrers) often misplace, or do not read, the information supplied in the leaflets suggesting that reports given about the information leaflet may not be entirely reliable. The leaflets did contain some information on the above areas, however, and if more information is supplied there is a risk that the leaflets will be too long and therefore less likely to be read.

Although the majority of patients were satisfied with the service, the findings suggest possible areas of improvement in the provision of future services. Although the waiting times were shorter in 1997 than in 1995, 10 weeks was still regarded as too long. However, it is anticipated that an opt-in system can be implemented in the near future with the aim of decreasing waiting time. It would appear that the Clinical Psychologist's explanation of their assessment needs to be clearer and that techniques employed and advice provided is understood and applicable for each individual patient. More attention may need to be paid to ensure that the patients both fully understand the advice given, and are able to carry it out effectively. One further area highlighted in this study was the need to improve strategies, such as relapse prevention, in order to increase the likelihood that gains made during therapy will be maintained after discharge.

Although the leaflet was helpful in providing information about what to expect before coming to see a Clinical Psychologist it may not have been beneficial in influencing expectations throughout treatment as this study indicated that there was no change in patient expectations regarding the outcome of therapy. Since patient expectations have been found to correlate with satisfaction <sup>9</sup> it may also be beneficial for patients to have

opportunities to discuss their continuing expectations throughout the course of therapy. Studies have demonstrated that asking individuals about their preferences for treatment options and incorporating their wishes into the formulation of treatment plans can have the effect of establishing more robust treatment alliances which in turn are central to predicting the efficacy of the treatment intervention itself. <sup>18</sup>

There were a number of limitations with this study. Firstly the number of subjects included in this study was small due to a slightly low return rate and hence conclusions need to be interpreted with caution. In addition, the 1997 group consisted of a proportion of the total referrals for that year. There may also have been a response bias which has been evident in previous consumer research studies. Dissatisfied patients may have been less likely to return the questionnaire than satisfied clients <sup>14</sup> producing positively skewed results. <sup>4</sup> However, it could be argued that dissatisfied patients may utilise the opportunity to express their complaints in the questionnaire. There was also no information on reliability and validity of the questionnaires used in this study which may have influenced the results. In addition, it is difficult to control departmental factors between 1995 and 1997, such as staffing changes, which may have impacted upon the results. Consequently future research into this area would need to take the above issues into consideration.

Patient satisfaction can be influenced by a multiplicity of patient, Clinical Psychologist, and external factors. Depending on individual variables, such as needs and type of problem, patients may respond to the service offered in different ways. Satisfaction can also be viewed as the difference between actual outcome of treatment and an individual's perception of an ideal outcome. <sup>1</sup> Some patients, for example, may expect long-term support, or a 24 hour service, which could affect perceived satisfaction with the service. Consequently, differing expectations may affect the way individuals report satisfaction with

the service. It may be necessary to differentiate different types of expectations because 'expectation' as a concept could be considered too broad. Future research could address this area by examining what types of expectations service users have, not only before attending, but also throughout the course of treatment. In addition, it may also be beneficial to examine what individual, therapist, and external factors influence patient expectations and to identify variations between the actual outcome of treatment and the patient's ideal outcome.

Nevertheless, despite these limitations, consumer opinion surveys can be used as an indicator of which aspects of services could be changed to improve responses.<sup>3</sup> Repeat studies are valuable in determining whether changes implemented after the findings of previous surveys have been beneficial in enhancing responses. Consequently, the above study would appear to suggest that repeat patient satisfaction studies can be a useful tool for assessing and improving patients' perception of the quality of services provided.

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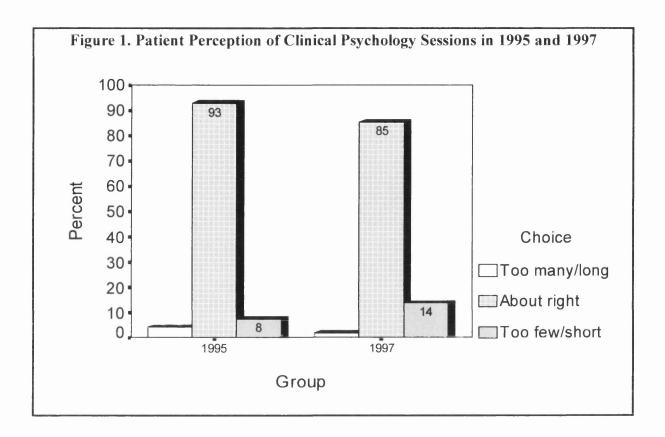
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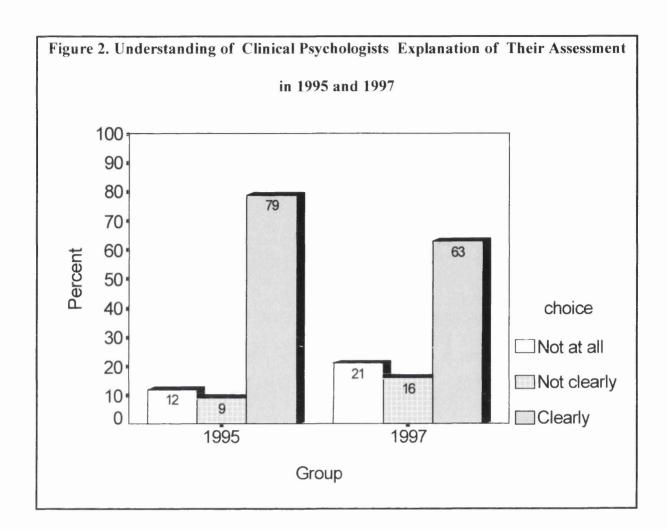
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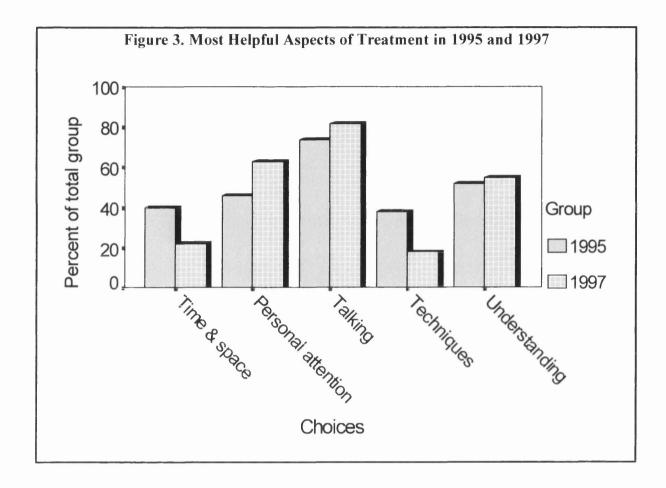
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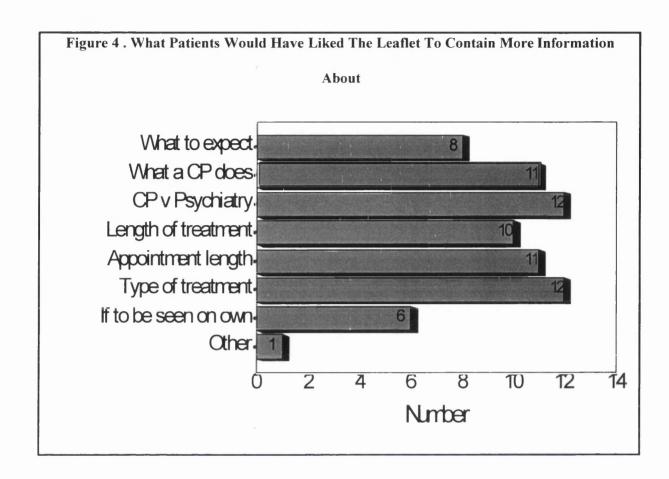
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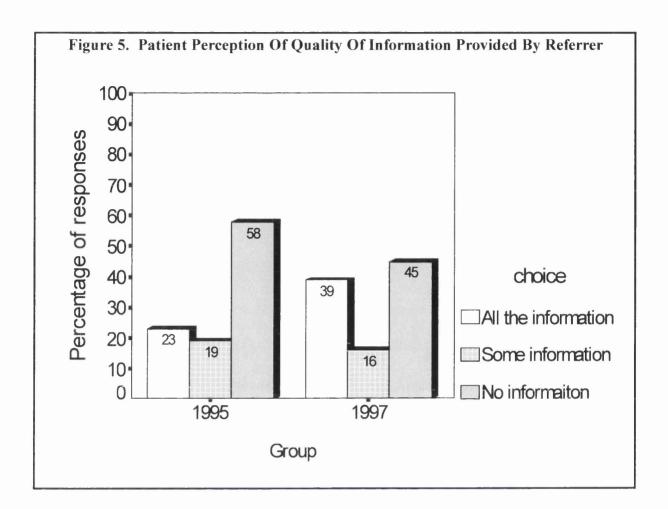


Table 1. Satisfaction With The Information Leaflet

| Question                                      | YES   | NO    | Significance   |
|---|-------|-------|----------------|
| Did you find the information leaflet helpful? | 39    | 3     | $X^2 = 30.9**$ |
|   | (93%) | (7%)  |                |
| Did the information leaflet contain enough    | 29    | 14    | $X^2 = 5.2 *$  |
| information about what to expect?             | (67%) | (33%) |                |
| When you saw the CP was it what you expected? | 33    | 16    | $X^2 = 5.9*$   |
|   | (67%) | (33%) |                |

n = 51; \*\* Chi-squared test for independence significant beyond the 0.001 level; \* Chi-squared test for independence significant beyond the 0.05 level

# 5. Research Case Study (Abstract)

Role of Attentional Bias In Panic Disorder in Adolescence:

A Single Case Study

Written in accordance with the guidelines for submission to:

Journal of Child Psychology and Psychiatry (see Appendix 5.1)

#### **ABSTRACT**

The investigation of cognitive bias associated with anxiety disorders in adolescence, is an area that has lagged behind similar research in adult populations. This single case study presents the experimental investigation of attentional bias, and subsequent treatment, in a thirteen year old adolescent with panic disorder using a computerised emotional Stroop task. In order to clarify whether attentional bias is involved in the maintenance of panic disorder, the study also aims to investigate whether attentional bias was present after brief CBT using a follow-up design. Response latencies for catastrophe and fear words, but not body words, was longer than neutral words which was suggestive of attentional bias for threat related material. These results suggested that cognition, associated with panic disorder in adolescence, may be centred around misinterpretations of physiological symptoms. Symptom improvement was associated with reduced attentional bias for these panic-related words at follow-up. This study also demonstrated the effectiveness of a brief CBT intervention for panic disorder in adolescence. The results are discussed in the context of the adult literature and the limited literature on cognitive processing in children and adolescents with anxiety disorders.

# APPENDICES

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### Appendix 1.1 Notes for Contributors: British Journal of Health Psychology

#### **NOTES FOR CONTRIBUTORS**

1. The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the Journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- (a) Papers reporting original empirical investigations
- (b) Theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations
- (c) Review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology
- (d) Methodological papers dealing with methodological issues of particular relevance to health psychology.
- The Journal is international in its authors and readers.
   Contributors should bear the international readership in mind, particularly when referring to specific health services.
- 3. Pressure on Journal space is considerable and brevity is requested. Papers should normally be no more than 5000 words.
- 4. Supplementary data too extensive for publication may also be deposited with the British Library Document Supply Centre. Such material should be submitted to the Editors together with the article for simultaneous refereeing. Further details of the scheme are given in the Bulletin of the British Psychological Society, 1977, 30, February, p. 58. A copy of that note may be obtained from the Journals Office.
- 5. This Journal operates a policy of blind peer review. Papers will normally be scrutinized and commented on by at least two independent expert referees as well as by an editor or associate editor. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page (and the text should be free of such clues as identifiable self-citations ('In our earlier work...').) The paper's title should be repeated on the first page of text.
- 6. The editors will reject papers which evidence discriminatory, unethical or unprofessional practices.
- Submission of a paper implies that it has neither been published elsewhere nor is under consideration by another journal.
- 8. In preparing material for submission authors should follow these guidelines:
- (a) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. Sheets must be numbered. Four good copies of the manuscript should be submitted and a copy should be retained by the author.
- (b) Tables should be typed in double spacing, each on a separate sheet of paper. Each should have a self-explanatory title and be comprehensible without reference to the text.
- (c) Figures are usually produced direct from authors'

- originals and should be presented as good black and white images preferably on high contrast glossy paper, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns or lines and shading should be avoided. Paperclips leave damaging indentations and should be avoided. Any necessary instructions should be written on an accompanying photocopy. Captions should be listed on a separate sheet.
- (d) The Editors propose to adopt structured abstracts and all articles should be preceded by a structured abstract of between 100 and 250 words (less in the case of a short paper), giving a concise statement of the intention and results or conclusions of the article. Authors requiring further details on structured abstracts should contact the Journals Office (details on inside front cover).
- (e) Bibliographic references in the text should quote the author's name and the date of publication thus: Hunt (1995). Multiple citations should be given alphabetically rather than chronologically: (Blackburn, 1996; Fortheringhame, 1994;

Norman, 1995). If a work has two authors, cite both names in the text throughout: Choi & Salmon (1995). In the case of reference to three or more authors, use all the names on the first mention and et al. thereafter except in the reference list.

- (f) References cited in the text must appear in the list at the end of the article. The list should be typed double spaced in the following format:
- Hunter, M. (1994). Counselling in Obstetrics and Gynaecology. Leicester: The British Psychological Society.
- Pruitt, S.D., & Elliott, C.H. (1989). Paediatric procedures. In M. Johnstone & L. Wallace (Eds), Stress and Medical Procedures, (pp. 157-174). Oxford: Oxford University Press.
- Ray, C., Phillips, L., & Weir, W.R.C. (1993). Quality of attention in chronic fatigue syndrome: Subjective reports of everyday attention and cognitive difficulty, and performance on tasks of focused attention. British Journal of Clinical Psychology, 32, 357-364.

Note that journal titles are cited without abbrevation.

- (h) Measurements should be in units of the International System. A guide to these is included in The British Psychological Society's Style Guide, available at £3.50 per copy from the Society at St Andrews House. 48 Princess Road East. Leicester LE1 7DR, UK.
- (i) If the title of the article is longer than 80 characters, a short title should be provided for use as a running head.
- (j) Footnotes are expensive to set and should be avoided.
- (9) Proofs are sent to authors for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the senior author, but further copies may be ordered on a form supplied with the proofs.
- (10) Authors should consult the Journal editor concerning prior publication in any form or in any language of all or part of their article.
- (11) To protect authors and journals against unauthorized reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to The Journal, authors will be requested to sign an appropriate assignment of copyright form.

# Appendix 2.1 Stroop Words (Red = R; Yellow = Y; Blue = B; Green = G)

# • CANCER WORDS

| Tumour (R)    | Doctor (B)   | Melanoma (G)   | Hospital (B)  |
|---------------|--------------|----------------|---------------|
| Future (Y)    | Pain (B)     | Death (G)      | Sickness (R)  |
| Treatment (B) | Surgery (G)  | Nausea (R)     | Mortality (G) |
| Illness (R)   | Weight (Y)   | Survival (B)   | Diagnosis (G) |
| Disease (R)   | Remission(Y) | Medication (Y) | Malignant (Y) |

#### • SLEEP WORDS

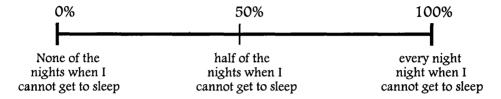
| Fatigue (B) | Alert (G)   | Silence (Y)    | Restless (G) |
|-------------|-------------|----------------|--------------|
| Sleepy (Y)  | Snoring (R) | Overactive (G) | Tired (R)    |
| Naps (Y)    | Wakeful (B) | Lethargy(Y)    | Dream (Y)    |
| Pillow (R)  | Tossing (B) | Exhausted (G)  | Sheets (G)   |
| Dark (B)    | Arousal (b) | Night (R)      | Bed (R)      |

# • NEUTRAL WORDS

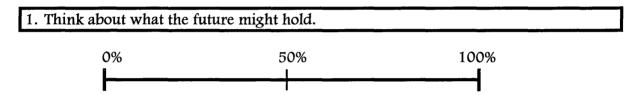
| Button (R)    | Saturday (Y)  | Set (R)        | Point (R)    |
|---------------|---------------|----------------|--------------|
| Drawing (B)   | Texture (Y)   | Watermelon (G) | Study (R)    |
| Pear (Y)      | Intellect (G) | Balcony (B)    | Нарру (В)    |
| Playful (R)   | Panorama (G)  | Same (B)       | Signal (Y)   |
| Praise (G)    | Sandwich (G)  | Whatever(Y)    | Nation (R)   |
| Substance (B) | Address (B)   | Bottle (Y)     | After (G)    |
| Shuffle (B)   | Defendant (Y) | Television (Y) | Mushroom(R)  |
| Library (G)   | Amazingly (G) | Banana (R)     | Queen (G)    |
| National(B)   | Window (R)    | Height (Y)     | Alphabet (B) |
| Cream (Y)     | Secretary (G) | Outside (R)    | Turn (B)     |

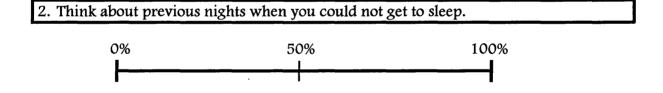
# SLEEP-ONSET THOUGHT SCALE - E (SOTS-E)

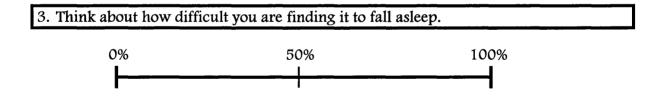
This questionnaire contains a list of thoughts that some people may experience on typical nights when they have been unable to get to sleep. Please think about typical nights when you have been unable to fall asleep over the past month and indicate by placing a mark on each line, using the scale below, that best shows how often you experience these thoughts while trying to fall asleep.

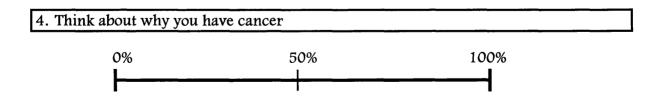


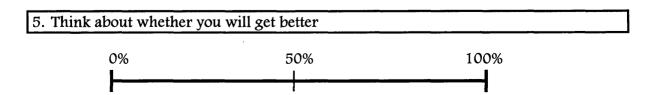
# START OF QUESTIONNAIRE

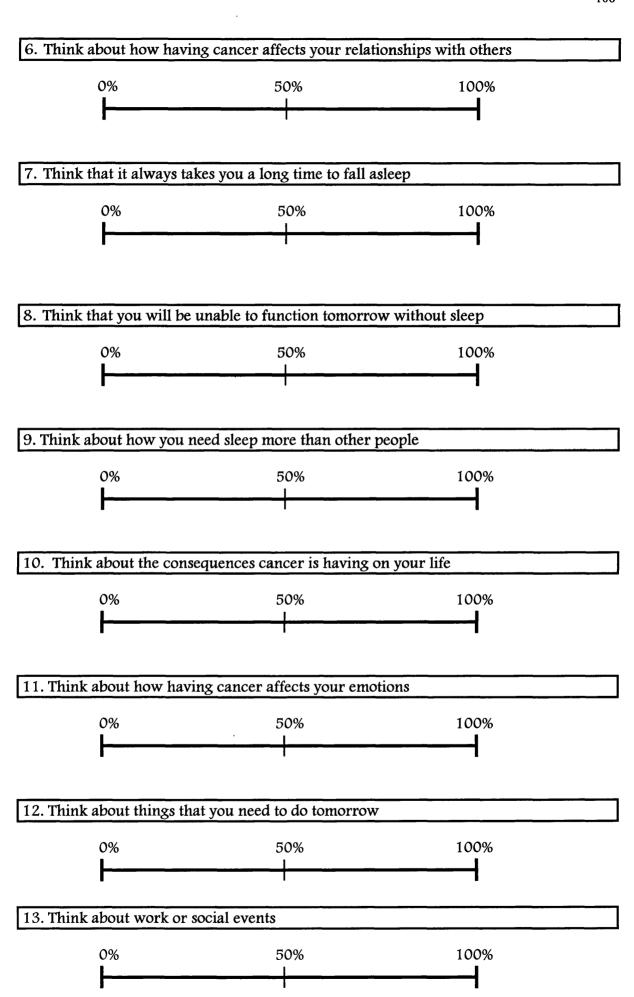


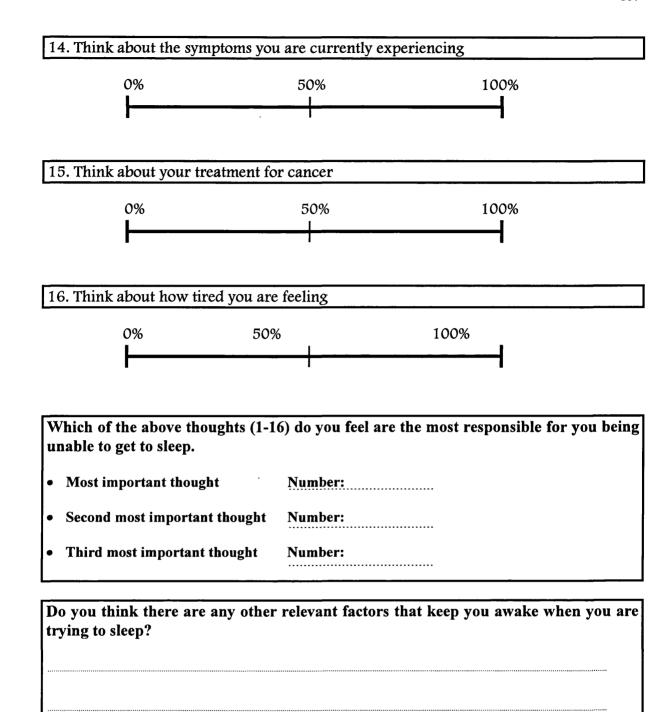








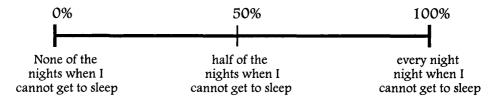




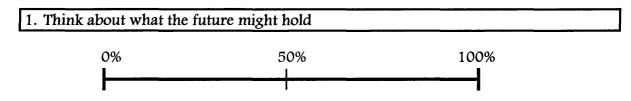
Thank you for taking the time to complete this questionnaire.

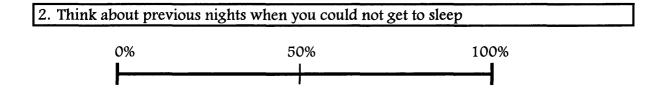
# SLEEP-ONSET THOUGHT SCALE - L (SOTS-L)

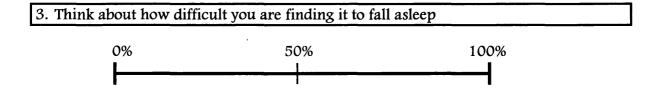
This questionnaire contains a list of thoughts that some people may experience on typical nights when they have been unable to get to sleep. Please think about typical nights when you have been unable to fall asleep over the past month and indicate by placing a mark on each line, using the scale below, that best shows how often you experience these thoughts while trying to fall asleep.

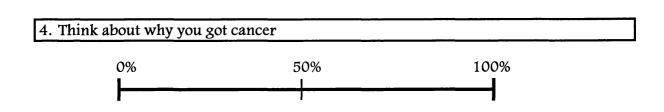


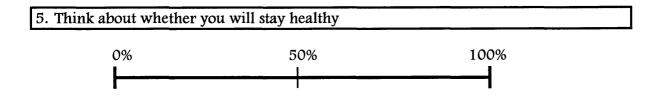
### START OF QUESTIONNAIRE

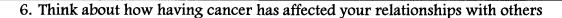


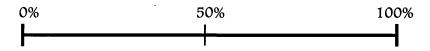




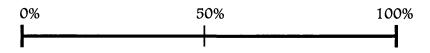




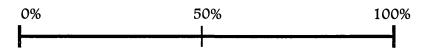




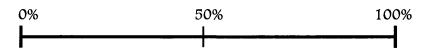
# 7. Think that it always takes you a long time to fall asleep



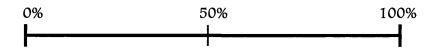
# 8. Think that you will be unable to function tomorrow without sleep



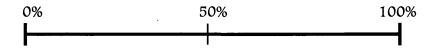
# 9. Think about how you need sleep more than other people



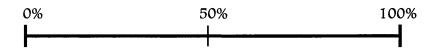
# 10. Think about the consequences cancer has had on your life

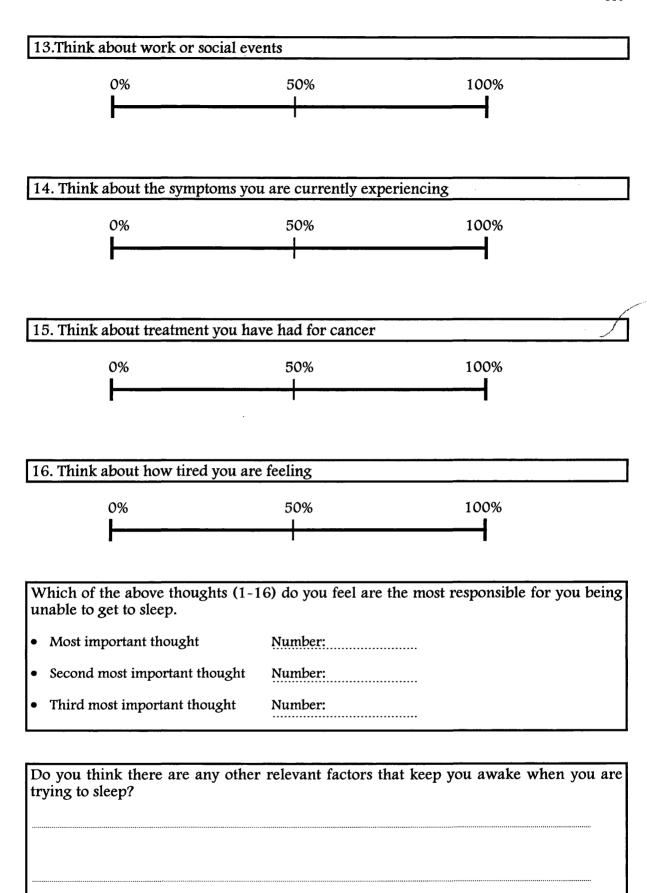


# 11. Think about how having cancer has affected your emotions



# 12. Think about things that you need to do tomorrow





Thank you for taking the time to complete this questionnaire.

#### **Appendix 2.4 - Information Sheet**

# THIS SHEET HAS BEEN APPROVED BY THE WEST ETHICS COMMITTEE INFORMATION SHEET FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

#### **Brief Title of Project:**

Pre-Sleep Thoughts Associated With The Evolution Of Sleep Problems In Cancer.

You have been invited to participate in a study being carried out by the Department of Psychological Medicine at the University of Glasgow. The aim of this study is to understand more about the types of thoughts that people with cancer may experience while trying to fall asleep.

#### **Purpose of Study**

A number of studies have noted that people who have had cancer commonly report difficulties with falling asleep. The aim of this study is to help us understand more about the way cancer affects our ability to get to sleep. This will involve considering what types of thoughts you experience while trying to fall asleep. Greater understanding about these thoughts may help prevent the development of sleep problems after a cancer diagnosis and allow for the development of more effective treatments.

#### **Procedure**

If you choose to participate in this study you will be asked to sign a consent form indicating that you have chosen to take part. You will then be asked to complete some questionnaires about your sleep, mood and thoughts. You will also be asked to identify colours of different words presented to you on a computer screen. It is hoped that involvement in this study will take about 30 minutes of your time.

Your participation in this study may be of no direct benefit to you, but could help in the development of treatments for future patients. All information you give as part of this research will be confidential. However, if any of your responses indicate that your mood is very low or that you are very distressed your consultant will be notified. If you wish to take part in this study, your General Practitioner will also be advised of your participation and the clinical management that you will undergo. If you do not wish to participate in this study or you wish to withdraw at any time after commencing, your care will in no way be affected. If you want to discuss the research further or you have any questions which you would like answered then please contact: Ms Lynne Taylor, Department of Psychological Medicine, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow; Tel: 0141-2110687.

Thank you for your interest in the study.

#### Appendix 2.5 - Consent Form

| WEST ETHICS COMMITTED |   |
|-----------------------|---|
|                       | r |

#### FORM OF CONSENT FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

#### **Title of Project:**

Pre-Sleep Thoughts Associated With The Evolution Of Sleep Problems In Cancer.

By signing this form you give consent to your participation in the project whose title is at the top of this page. You should have been given a complete explanation of the project to your satisfaction and have been given the opportunity to ask questions. You should have been given a copy of the patient information sheet approved by the West Ethics Committee to read and to keep. Even though you have agreed to take part in the research procedures you may withdraw this consent at any time without the need to explain why and without any prejudice to your care.

| Consent:   |
|--|
| I,(PRINT)  |
| of   |
| give my consent to the research procedures above, the nature, purpose and possible consequences of which have been described to me |
| by   |
| Patient's signature  |
| Doctor's signature   |

WEST ETHICS COMMITTEE

211 1920

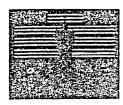
Western Infirmary

Direct Line: 211 6238

Dumbarton Road Glasgow G11 6NT

Fax:

### Appendix 2.6 - Letter of Approval - West Ethics Committee



# West Glasgow Hospitals University NHS Trust

Our Ref:

AHT

Your Ref:

Please reply to: Mrs A H Torrie

SECRETARY - WEST ETHICS COMMITTEE

21 July, 1999

Ms L M Taylor Clinical Psychologist in Training Dept of Psychological Medicine Gartnavel Royal Hospital Glasgow

Dear Ms Taylor,

99/129(2) Ms Lynne M. Taylor et al - The evolution of sleep-onset latency problems in cancer: An investigation into pre-sleep thoughts.

The Committee at the meeting held on 20th July, 1999 discussed the above study and approved the study design but did wonder if you might consider repeating the questionnaire 2 weeks later to see if patients sleep patterns have altered. The Committee also require that a sentence should be added to the Patient Information Sheet informing the GP if the patient takes part. The above minor amendments should come back to me for filing. This study now has full Ethics Committee approval.

Kind regards.

Yours sincerely,

Andrea H Torrie

Midra A Line

**SECRETARY - WEST ETHICS COMMITTEE** 



### Appendix 2.7 - Letter of Approval - Ayrshire and Arran Health Board



HEAD OFFICE Boswell House 10 Arthur Street Ayr KA7 1QJ

Tel: (01292) 611040 Fax: (01292) 885890

Our Ref.

2.0

AC1-29/MG

Your Ref.

DDI:

01292 885859

16 November 1999

Ms L M Taylor
Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12 0XH

Dear Ms Taylor

The evolution of sleep-onset latency problems in cancer: An investigation into pre-sleep thoughts

I am pleased to inform you that the Research Ethics Committee at their meeting on 5 November 1999 granted ethical approval for the above study to go ahead.

The terms of approval state that:

- You must clarify the strategy to be adopted in the case of colour blind respondents taking the Stroop test.
- The written consent of patients participating in the study must be obtained. The patient information sheet and consent form and the manner in which you intend to seek consent are acceptable.
- Regular reports on the progress of the study require to be submitted and your first report should be submitted to myself in six months time and subsequently at yearly intervals until the work is completed.
- As indicated in the guidance notes to researchers, a copy of which you were supplied with, you will require to seek the permission of the responsible NHS body within the Board's area prior to proceeding with this project. In this respect you should contact Mr Gerry Watson, Medical Director of the Ayrshire & Arran Acute Hospitals NHS Trust, to confirm that management have no objections to the study going ahead.

# 3.1 Notes for Contributors: Journal of Abnormal Psychology

# Instructions to Authors Journal of Abnormal Psychology

Most of the articles published in the Journal of Abnormal Psychology are reports of original research, but other types of articles are acceptable. Short Reports of replications or of failures to replicate previously reported results are given serious consideration. Comments on articles published in the journal are also considered. Case studies from either a clinical setting or a laboratory will be considered if they raise or illustrate important questions that go beyond the single case and have heuristic value. Manuscripts that present or discuss theoretical formulations of psychopathology, or that evaluate competing theoretical formulations on the basis of published data, may also be accepted. For further information on content, authors may refer to the Journal Description.

Authors must prepare manuscripts according to the Publication Manual of the American Psychological Association (4th ed.). All manuscripts must include an abstract that contains a maximum of 960 characters and spaces (which is about 120 words) typed on a separate sheet of paper. All copy must be double-spaced, and further typing instructions, especially in regard to tables, figures, references, metrics, and abstracts, appear in the Manual. Also, all manuscripts are copyedited for bias-free language (see chap. 2 of the Publication Manual). Original color figures can be printed in color provided the author agrees to pay half of the associated production costs.

In preparing a Short Report, authors should set the character-space limit at 60 characters per line and should not exceed 410 lines of text and references (exclusive or the title page, abstract, author note, footnotes, tables, and figures). There should be no more than two figures or tables. As for regular manuscripts, the abstract must not exceed 960 characters and spaces.

Masked reviews are optional, and authors who wish masked reviews must specifically request them when they submit their manuscripts. For masked reviews, each copy of the manuscript must include a separate title page with the authors' names and affilitations, and these ought not to appear anywhere else in the manuscript. Footnotes that identify the authors must be typed on a separate page. Authors are to make every effort to see that the manuscript itself contains no clues to their identities.

Articles, except where other limits are specified, must not be longer than 36 manuscript pages, unless they report an unusually large series of studies or present unusually important detail. Case studies are ordinarily no longer than 16 manuscript pages. Comments ought not to exceed half the length of the original article. For Short Reports, the length limits are exact and must be strictly followed.

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications. In addition, it is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 6.24). As this journal is a primary journal that publishes original material only, APA policy prohibits as well publication of any manuscript that has already been published in whole or substantial part elsewhere. Authors have an obligation to consult journal editors concerning prior publication of any data upon which their article depends. In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 6.25). APA expects authors submitting to this journal to adhere to these standards. Specifically, authors of manuscripts submitted to APA journals are expected to have available their data throughout the editorial review process and for at least 5 years after the date of publication.

Authors will be required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment. A copy of the APA Ethical Principles may be obtained by writing the APA Ethics Office, 750 First Street, NE, Washington, DC 20002-4242.

Authors submit five (5) copies of their manuscripts. All copies must be clear, readable, and printed on paper of good quality. A dot matrix or unusual typeface is acceptable only if it is clear and legible. Dittoed or mimeographed copies are not acceptable and will not be considered. It is suggested that authors keep a copy of the manuscript to guard against loss. Manuscripts are not returned except on request.

In addition to postal addresses and telephone numbers, authors are requested to supply electronic mail addresses and fax numbers, if available, for use by the editorial and production offices. Effective in January 2000, the Incoming Editor is receiving all submissions to the journal. Submissions that are accepted will be published beginning in the 2001 volume. Mail manuscripts to the Incoming Editor, Timothy B. Baker, Department of Psychology, University of Wisconsin—Madison, 1202 West Johnson Street, Madison, Wisconsin 53706.

Appendix 3.2: Cancer Types Included In Study

|               | Early Group  | Late Group   |
|---------------|--------------|--------------|
|               | (% of total) | (% of total) |
| Breast Cancer | 9 (50%)      | 8 (53%)      |
| Ovarian       | 3 (17%)      | 1 (7%)       |
| ALL           | 2 (11%)      | 2 (13%)      |
| Larynx        | 1 (5.5%)     | 0 (0%)       |
| Testicular    | 1 (5.5%)     | 1 (7%)       |
| Hodgkin       | 1 (5.5%)     | 2 (13%)      |
| Thyroid       | 0 (0%)       | 1 (7%)       |
| Lung          | 1 (5.5%)     | 0 (0%)       |

#### 3.3 Sleep items from SOTS Included and Excluded from the Analysis

### **5 SLEEP ITEMS INCLUDED IN THE ANALYSIS**

Items developed from the cognitive sleep category, thinking about sleep and it's consequences Wicklow and Espie (2000)

Item Number 2: Think about previous nights when you could not get to sleep.

Item Number 3: Think about how difficult you are finding it to fall asleep.

Item Number 7. Think that it always takes you a long time to fall asleep.

Item Number 8: Think that you will be unable to function tomorrow without sleep.

Item Number 9: Think about how you need sleep more than other people

### THREE AMBIGIOUS SLEEP ITEMS EXLUDED FROM THE ANALYSIS

Items developed from the problem solving category

Wicklow and Espie (2000)

Item Number 12: Think about things that you need to do tomorrow

Item Number 13: Think about work or social events

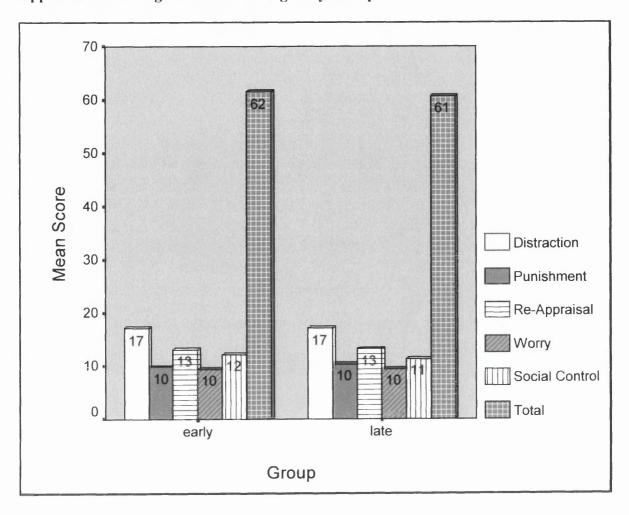
Item Number 16: Think about how tired you are feeling

Appendix 3.4 Mean Rank Scores for SOTS by VAS and Top Three Ranking of Items (including 3 ambiguous items)

|                        | Early Group | Late Group | Mann-Whitney |
|------------------------|-------------|------------|--------------|
|                        | Mean Rank   | Mean Rank  | Test         |
| VAS Eight Cancer Items | 18.3        | 16.6       | U = 130.5    |
|                        |             |            | p = 0.64     |
| VAS Eight Sleep Items  | 16.2        | 17.9       | U = 121.0    |
|                        |             |            | p = 0.61     |
| Top Three Ranking for  | 19.7        | 13.8       | U = 86.5     |
| Cancer Items           |             |            | p = 0.08     |
| Top Three Ranking for  | 14.5        | 19.9       | U = 86.5     |
| Sleep Items            |             |            | p = 0.07     |

n=33

Appendix 3.5 Thought Control Strategies by Group



#### 4.1 - Notes for Contributors: Health Bulletin

#### Notes for Contributors

Papers, articles and other contributions should be sent to the Editor, Health Bulletin, Scottish Executive Health Department, Room IE05, St Andrew's House, Edinburgh EH1 3DE. They must be submitted exclusively for Health Bulletin. Acceptance is on the understanding that editorial revision may be necessary. All papers are reviewed by the Editor and by peer review, referees being drawn from a panel of appropriate professionals. No correspondence can be entered into in relation to articles found to be unsuitable and returned to authors.

Potential contributions can be submitted in two ways. Material submitted for publication must be typewritten on one side of the paper only, in double spacing and with adequate margins, and each page should be numbered. The top typed copy should be submitted, with four other copies. We are willing to receive one copy typewritten in the above format and accompanied by a disk (Microsoft Word version 98, Excel for tables and figures). All papers should be prefaced by a structured Abstract, of about 250 words in length. It should normally contain six clearly headed sections entitled Objective, Design, Setting, Subjects, Results and Conclusion. The name, appointment and place of work of the authors should be supplied on a separate title page. This same page should include the full postal address of one author, to whom correspondence and reprints will be directed. There should be adequate references to any relevant previous work on the subject; these references should appear at the end of the material on a separate page or pages, using the Vancouver style, which in the case of papers in journals includes:

Surname and initials of author(s)
Title of paper
Full name of journal
Year published
Volume number
Opening and closing page numbers

Reference to books should similarly include author's name and initials, full title, edition (if necessary), place of publication, publisher's name, year and, if required, volume number, chapter number or page number.

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# SATISFACTION QUESTIONNAIRE - CP

These questionnaire is designed to assess what you think of the Clinical Psychology Service. Please read the following questions carefully and tick the most appropriate answer/s.

| 1. How long did you have to wait between being referred appointment?  | to the psychologist and your first |
|---|------------------------------------|
|   | MEERC                              |
| Please tick one answer for the following questions:   | WEEKS                              |
| I tease tick one answer for the following questions.  |                                    |
| 2. Do you have any problems travelling to the clinic?   |                                    |
|   | Yes                                |
|   | No                                 |
| If yes what are these problems:   |                                    |
|   |                                    |
|   |                                    |
|   |                                    |
|   |                                    |
| 2 1871  |                                    |
| 3. Who referred you to the Psychology department?   | GP                                 |
|   | Psychiatrist Psychiatrist          |
|   | Other                              |
|   | Other                              |
| 4. Were you given any information before your first appoint you about what to expect when you came to the clinic? | ntment by the person that referred |
|   | All the information I required     |
|   | Some, but I would have liked       |
|   | more                               |
|   | I received no information          |
| 5. Were you given any information from anyone else abopsychologist?   | out what to expect from seeing a   |
| 1 7 8   | Yes                                |
|   | No                                 |
| If yes who:   |                                    |
|   |                                    |
| ·   |                                    |
| 6. Did you find the information leaflet that was sent to you leaflet!   | before your first appointment      |
| •   | Yes                                |
|   | NT.                                |
|   | No                                 |

|   | Yes                                  |
|---|--------------------------------------|
|   | No                                   |
| If you answered No, would you have liked more details Please tick all that are appropriate:               | s in the information leaflet about:  |
| a) what to expect from your first appointment   |                                      |
| b) what a clinical psychologist does  |                                      |
| c) the difference between a psychologist and a psychiatris  | st                                   |
| d) how long treatment would last  |                                      |
| e) how long each appointment would last   |                                      |
| f) about what type of treatment you would be receiving  |                                      |
| g) whether you would be see on your own or with your pa   | artner                               |
| h) other: (please state)  |                                      |
| Please tick one answer for the following questions: 8. When you saw the psychologist was it what you expe | poted?                               |
| o. When you saw the psychologist was it what you expe   | Yes                                  |
|   | No                                   |
|   |                                      |
| 9. Are you seen at:   |                                      |
|   | Dumbarton Joint Hospital             |
|   | Vale of Leven District General       |
|   | Hospital                             |
|   | Bank Street Clinic                   |
|   | Victoria infirmary, Helensburgh Home |
|   | Home                                 |
| 10.Do you feel that what you tell the psychologist rema   | ins private and confidential:        |
|   | Yes                                  |
|   | No                                   |
|   |                                      |
| 11. What do you think of:   |                                      |
| a) the length of sessions with the psychologist?  | T. 1                                 |
|   | Too long                             |
|   | About right                          |
|   | Too short                            |
| b) the number of sessions with the psychologist?  |                                      |
| b) the number of sessions with the psychologists  | Too many                             |
|   | About right                          |
|   | Too few                              |
| c) the frequency of sessions with the psychologist?   |                                      |
| 1 0   | Too often                            |
|   | About right                          |
|   | Too few                              |
|   |                                      |

7. Did you feel the information leaflet contained enough information about what to expect?

| 12. At your first appointment did the psychologist explain                | their assessment to you?                          |
|---|---|
|   | Not at all  |
|   | Yes but no clearly                                |
|   | Yes, clearly                                      |
| 13. Was the advice you were given realistic, i.e. could you               | use it in everyday life?                          |
|   | Rarely  |
|   | Some of the time                                  |
|   | Most of the time                                  |
| 14. Did you have enough time to discuss your problems?                    |   |
|   | Some of the time                                  |
|   | Most of the time                                  |
|   |   |
| 15. What do you find the most helpful part/parts of your t                |   |
| Plea  | se tick all that are appropriate:  Time and space |
| •   | Personal attention                                |
|   | Talking   |
|   | Techniques  |
|   |   |
|   | Understanding                                     |
| 16. Do you have anything else you would like to add a psychology service? |   |
|   |   |
|   |   |
|   |   |
|   |   |
| psychology service?   |   |

# SATISFACTION QUESTIONNAIRE - DP

These questionnaire is designed to assess what you think of the Clinical Psychology Service. Please read the following questions carefully and tick the most appropriate answer/s.

| 1. How long did you have to wait between being referred appointment?  | to the psychologist and your first |
|---|------------------------------------|
|   | WEEKS                              |
| Please tick one answer for the following questions:   |                                    |
| 2. Did you have any problems travelling to the clinic?  |                                    |
|   | Yes                                |
|   | No                                 |
| If yes what were these problems:  |                                    |
|   |                                    |
| 3. Who referred you to the Psychology department?   |                                    |
|   | GP                                 |
|   | Psychiatrist                       |
| 4. Were you given any information before your first appoing you about what to expect when you came to the clinic? | ntment by the person that referred |
|   | All the information I required     |
|   | Some, but I would have liked more  |
|   | I received no information          |
| 5. Were you given any information from anyone else about psychologist?  | what to expect from seeing a       |
|   | Yes                                |
|   | No                                 |
| If yes who:   |                                    |
|   |                                    |
| 6. Did you find the information leaflet that was sent to y helpful?   | ou before your first appointment   |
|   | Yes                                |
|   | No                                 |
| 7. Did you feel the information leaflet contained enough info   |                                    |
|   | Yes                                |

No

| If you answered No, would you have liked more detai  | ls in the information leaflet about: |
|--|--------------------------------------|
| Please tick all that are appropriate:  |                                      |
| a) what to expect from your first appointment  |                                      |
| b) what a clinical psychologist does   |                                      |
| c) the difference between a psychologist and a psychiatr   | rist                                 |
| d) how long treatment would last   |                                      |
| e) how long each appointment would last  |                                      |
| f) about what type of treatment you would be receiving   |                                      |
| g) whether you would be see on your own or with your   | partner                              |
| h) other: (please state)   | ,                                    |
| Please tick one answer for the following questions: 8. When you saw the psychologist was it what you exp | pected?                              |
| , , ,  |                                      |
|  | Yes                                  |
|  | No                                   |
|  |                                      |
| 9. Were you see at:  |                                      |
|  | Dumbarton Joint Hospital             |
|  | Vale of Leven General Hospital       |
|  | Bank Street Clinic                   |
|  | Victoria Infirmary, Helensburgh      |
|  | Home                                 |
| 10.Did you feel that what you told the psychologist re   | mained private and confidential:     |
|  | No                                   |
| 11. What do you think of:  |                                      |
| a) the length of sessions with the psychologist?   |                                      |
| •  | Too long                             |
|  | About right                          |
|  | Too short                            |
| b) the number of sessions with the psychologist?   |                                      |
|  | Too many                             |
|  | About right                          |
|  | Too few                              |
| c) the frequency of sessions with the psychologist?  |                                      |
|  | Too often                            |
|  | About right                          |

Too few

| 12. At your first appointment did the psychologist explain t  | their assessment to you?          |
|---|-----------------------------------|
|   | Not at all                        |
|   | Yes but not clearly               |
|   | Yes, clearly                      |
| 13. Was the advice you were given realistic, i.e. could you u | se it in everyday life?           |
|   | Rarely                            |
|   | Some of the time                  |
|   | Most of the time                  |
| 14. Did you have enough time to discuss your problems?        |                                   |
|   | Some of the time                  |
|   | Most of the time                  |
|   |                                   |
| 15. What did you find the most helpful part/parts of your to  |                                   |
| Pleas   | e tick all that are appropriate:  |
|   | Time and space Personal attention |
|   |                                   |
|   | Talking                           |
|   | Techniques                        |
| Places tick one anamon for the following questions:           | Understanding                     |
| Please tick one answer for the following questions:           |                                   |
| 16. How helpful did you find your treatment?                  | X 1 . C. 1                        |
|   | Very helpful                      |
|   | On the whole helpful              |
| TC 1 1 C4-11 '414-10  | Not very helpful                  |
| If you have benefited has it lasted?                          | Yes                               |
|   | No                                |
|   | No                                |
| 17. Was the result of treatment what you expected?            |                                   |
|   | Yes                               |
|   | No                                |
| If not what had you expected?                                 |                                   |
|   |                                   |
|   |                                   |
|   |                                   |
|   |                                   |
|   |                                   |
| 18. Do you think that the treatment ended at:                 | lm : 1                            |
| ·   | The right time                    |
|   | Too soon                          |

| 19. At the end of your treatment were you offered any of t                | ine following:                      |
|---|-------------------------------------|
| Plea  | se tick all that are appropriate:   |
|   | Follow-up appointments              |
|   | Contact psychologist                |
|   | Referral to someone else            |
|   | Other                               |
| 20. Did you stop attending your appointments before the                   | end of your treatment?              |
|   | Yes                                 |
|   | No                                  |
| If Yes what were your reasons?  |                                     |
|   |                                     |
|   |                                     |
| ·   |                                     |
|   |                                     |
|   |                                     |
|   | · <del></del>                       |
| 21. Do you have anything else you would like to add a psychology service? | bout your contact with the clinical |
| • • • •   | bout your contact with the clinical |
| • • • •   | bout your contact with the clinical |
| • • • •   | bout your contact with the clinical |
| • • • •   | bout your contact with the clinical |
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