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Promoting Couple Support in Cancer

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This doctoral portfolio is almost exclusively about the psychological effects of cancer. In view of the fact that one in three people will develop cancer in their lifetime, and that a third of these people will develop significant psychological problems, it is fitting that clinical psychology is increasingly turning its attention to this important area of human experience. Psycho-oncology is a small but growing field with many significant questions still to be answered.

It could be argued that the public's dread of cancer, as a physically wasting and unremittingly painful disease, is misplaced. The growth of palliative medicine from its origins in the hospice movement, have led to enormous advances in symptom control. Rarely is physical suffering an issue where palliative care services are well developed. However, the psychological effects of cancer probably bear a much closer resemblance to common images of the disease as wasting and painful. The trauma of diagnosis heralds turbulent and far-reaching changes in a person's psychological and social world, many of which slowly eat into the fabric of people's lives. As yet, the small field of psychosocial oncology has had little impact on the urgent need to help people negotiate this time of personal crisis and prevent some of the suffering associated with it. Thus, all three parts of this portfolio concerned with cancer attempt to take an implicitly preventative perspective.

The first review paper examines the evidence for whether the diagnosis of cancer constitutes a trauma leading to post-traumatic stress disorder, and what this implies for improving the way in which the diagnosis is delivered. My interest in this area stems from my patients' apparent need to talk about this particular moment in their cancer journey, the bad experiences many of them recount, and their often persistent and intrusive memories of it.

The second paper concerns what the lay person refers to as the process of "coming to terms with cancer"; in other words, the psychological adjustments that people make in the process of restoring some quality to their lives in light of the implications of their disease. This prolonged period of psychosocial transition is the fertile ground from which psychological disorders develop yet, despite their crucial role, the processes of adjustment have rarely been articulated or even described within the field of psychosocial oncology.

The clinical research is a randomised controlled trial of an intervention designed to prevent psychological problems by enhancing the effectiveness of couple support. The motivation for this research again came directly from my clinical work. Over the past few years, I have met countless women who have expressed profound disappointment and disillusionment at the level and quality of support they have received from their male partners; a story I have virtually never heard from a man.

Finally, I have attempted to inject the clinical audit paper with something of a personal tone in the belief that, more than most professions, clinical psychology necessitates personal involvement. The paper attempts to address some of the innate contradictions which appear to exist within clinical psychology, taking the trainee selection process as an example.
PERSONAL STUDY PLAN

CRITICAL REVIEW 1

The symptoms of distress and disorder which commonly follow the diagnosis of a life-threatening event have a number of parallels with the symptoms of Post-Traumatic Stress Disorder (PTSD). There is a recent surge in both theoretical and experimental understanding of PTSD as well as a number of recent attempts to find PTSD symptoms in newly diagnosed patients. However the latter literature is small and appears to lack a theoretical conception of PTSD phenomena.

The proposed literature review will critically examine attempts to explain the symptomatology of post-diagnosis distress in terms of PTSD. It will use current theoretical understanding of PTSD in order to make testable predictions of the psychological processes which may be occurring during the post-diagnostic period. The review may include:

- Introduction
- Concept of a traumatic stressor and PTSD
- What would constitute evidence that diagnosis is a traumatic stressor?
- Qualitative review of the diagnostic procedure and its effects
- Relationship between psychological morbidity and methods of delivering diagnoses, if any empirical work exists
- Diagnostic criteria for post-traumatic stress disorder
- Current theories of PTSD
- ? Links between PTSD and psychological symptoms in cancer and other diseases (AIDS, MS, Motor Neurone Disease etc, cardiac disease?)
- Controlled studies on PTSD following a diagnosis.
- Research questions and implications for how bad news is broken, service delivery and therapeutic interventions
A Critical Review of the Concept of Psychological Adjustment to the Diagnosis of Cancer

The concept of adjustment is widely used in the health psychology literature though it is rarely defined or operationalised. The term is often used to describe outcome measures that often simply denote the presence or absence of psychopathology. There is an apparent lack of any explicit theoretical basis for the way in which the term adjustment is used.

Thus this proposed literature review will consider the concept of 'adjustment' as it is used in the cancer literature, as well as problems of defining it. Further areas to be explored may include:

- What are the components of a normal adjustment? What is being 'adjusted'?
- Implicit and explicit theories of adjustment
  - Relationship between 'adjustment' and 'coping'
  - Coping theory
  - Other cognitive theories of adjustment
    - Traumatic stress
    - 'Psychosocial transitions'
- Evidence for factors which affect adjustment:
  - Personality (Watson's mental adjustment to cancer, etc)
  - Personal history (prior exposure, sensitisation)
  - Psychological/psychiatric history
  - Control through information
  - Self-efficacy vs learned helplessness
  - Social support as buffer
- Summary of problems with the concept of adjustment
- Relationship to quality of life
- Research questions

CLINICAL AUDIT

The practice of clinical psychology rests on the assumption that, by the end of their training, practitioners have received sufficient instruction in the theory and intervention techniques of the discipline to be allowed to practise safely. It will be argued that the most important variable in whether or not a person develops
into an effective practitioner may be missing from the clinical training
programme.

It will be asserted that it is the personality and personal history of the
practitioner which will in large part determine the nature of interactions with
clients and colleagues, not the techniques which they may be able to offer.
Increased self-awareness is often one of the more tangible benefits of
psychological intervention for many patients but how much self-awareness is
expected of the psychologist? One of the goals of most psychotherapies is to
allow individuals to regain control over their lives, in order that they can make
decisions freely with due consideration of internal and external pressures acting
upon them. Are we able to practise what we preach? How much of our career
development is the result of unexamined conflicts which we are attempting to
resolve through the practice of clinical psychology? And what effect may this be
having on our clients? What implications does this have for the way in which
clinical psychologists are trained and assessed, and monitored over the course of
their career?

This paper will deliberately be something of a personal statement in order to
make a professional point: that a quest for self-awareness is not necessarily
wrong and may, indeed, represent a necessary source of motivation for
individuals to enter the profession. However, it points to the need for training
courses and the profession to address issues of personal therapy, clinical
supervision and unconscious motivation throughout the career of the individual.
I will argue that there are inherent contradictions both in assessing clinical
psychology trainees on a purely academic basis, as well as introducing methods
(used by psychoanalysts) whereby trainees' personal therapy is used as part of
their assessment.
RESEARCH PROJECT

Promoting Social Support among Couples Affected by Cancer

Introduction
One in three people develop cancer in their lifetime; one in four people will die from it (Cancer Research Campaign, 1989). Between 15 and 20% of cancer patients will develop moderate to severe psychological disorders requiring mental health intervention. A further 30% will develop an adjustment disorder involving symptoms of anxiety or depression (Massie and Holland, 1990). This high incidence of psychological distress and disorder in such a prevalent disease poses a profound challenge to the small but growing field of psychosocial oncology (Maguire, 1995). It would be unrealistic to assume that there will ever be sufficient clinical resources within the National Health Service to meet this level of need. What is urgently required is a better understanding of the psychological processes which lead to these clinical disorders, and some empirically validated ways of preventing them from developing.

The diagnosis of cancer is, for most people, a traumatically stressful event which precedes the rapid onset of a bewilderingly complex medical treatment involving a combination of surgery, radiotherapy, chemotherapy and/or hormone treatments. For many, it is that start of a personal ‘cancer journey’ that may take many months to complete, during which time the individual may have had to make dramatic changes in their lifestyles and role relationships. In view of the stress of these many changes, and the uncertainties surrounding a life-threatening illness such as cancer, it might seem, intuitively, unsurprising that so many people develop high levels of anxiety and depression. Indeed, it has been argued that the diagnosis of cancer involves a great deal of human distress that is appropriate to the situation and it would be a mistake to ‘pathologise’ or ‘medicalise’ these experiences; on the contrary, they may lead to personal growth and development (Brennan and Sheard, 1994). However, the clinical
disorders that so often develop following the diagnosis of cancer are real and the purpose of the proposed study is to investigate one possible way of mitigating the stress of cancer and thereby preventing the development of psychological disorders.

There are a number of possible approaches to prevention that would appear to hold promise. A few examples follow:

- helping patients maintain their motivational structures by encouraging them to stay engaged with life (e.g. mastery and pleasure activity scheduling)
- helping patients regain a sense of personal control through obtaining information about their disease and its treatment and through learning to be more assertive with health care professionals
- providing a brief intervention to enhance patients' self-esteem (e.g. focusing on the role relationship changes in the patient's personal and working life.)
- providing patients with access to low-level social support (e.g. volunteer ex-patients) during the period soon after diagnosis.
- enhancing the role of the patient's partner in providing emotional support to the patient.

It is the last of these that this proposal seeks to address.

**Background**
Since the 1970s, associated in the U.K. with the pioneering work of Brown and Harris (1978), a growing body of literature has supported the assertion that social support may act as a buffer against stress. In spite of conceptual and methodological problems within this field, the assertion appears to be valid in the case of cancer (Wortman, 1984); that is, social support may constitute an important resource in coping with cancer.

Studies have shown that people with cancer require significant amounts of empathic support from other family members yet prefer not to seek advice or information from this source (Neuling and Winefield, 1988). Furthermore, it is
emotional, empathic support that appears to be most important where the individual perceives that they have little control over the stressor (Cutrona, 1990). A perception of lack of control is certainly the case in cancer. Other studies have shown that when people have an emotional concern they are most likely to turn to their spouse or partner (Barker, Pistrang, Shapiro and Shaw, 1990).

On the basis of these findings, Pistrang and Barker (1992) studied who women turn to for emotional support when they have breast cancer. They found that while 51% of those who had a partner regarded their partner as their 'most important helper', 38% of those who had nominated their partner as their preferred helper prior to breast cancer no longer regarded him as their preferred helper. The authors noted that women reported more problematic communication with partners than with friends and relatives. They concluded that their data suggest that “the communication problems with partners were more to do with men’s difficulties in dealing with feelings, rather than an inability to understand the women’s concerns.” (p.190)

Using subscales from the Symptom Check List (SCL-90R) and the Profile of Mood States, Bi-polar form (POMS-BI), Pistrang and Barker (1995) later reported that satisfaction with the partner helping relationship was associated with psychological well-being in breast cancer patients. Good communication with the partner was characterised by high empathy and low withdrawal, though women with partners were generally more distressed than women without partners. These authors also found that support from relationships outside the partner relationship did not compensate for the lack of a confiding relationship with the partner. They concluded that a poor partner relationship appears to be a risk factor in women’s psychological responses to breast cancer.

In an interview study of 56 Swedish couples in which the woman had breast cancer, other authors (Omne-Ponten, Holmberg, Sjoden and Berstrom, 1995) found that the husband’s assessment of the marital support, communication and
relationship was significantly related to the patient's psychosocial outcome at 13 months, though the study failed to use a standardised measure of psychological distress.

There is growing evidence that spouses of cancer patients suffer high levels of psychological distress. In a recent study (Glasdam, Jensen, Madsen and Rose, 1996), 120 spouses of consecutive patients with primary cancer were asked to complete a Hospital Anxiety and Depression scale. 18% scored as cases on the anxiety subscale (with a further 32% scoring as borderline cases) and 6% scored as cases on the depression subscale. Interestingly, although spouses reported that their contact with family and friends had been maintained or even intensified, only a third reported feeling any support from these sources. This is a potentially important finding since it is likely that people who are well supported are better able to give support.

In conclusion, it would appear that the patient-partner relationship has an important influence on the psychological adjustment of the patient. There may be a number of reasons why spouses fail to provide optimal support for their partners though one of these may be the fact that the carer-spouse may feel poorly supported themselves. Moreover, clinical experience suggests that patients sometimes 'protect' their spouses from their own distress and fail to discuss important issues they would otherwise wish to explore for fear of being a "burden" on their already distressed partners. Partners, in turn, may attempt to be over-protective or overly 'positive', or they may simply be afraid of further upsetting the patient by discussing their own distress. However, clinical experience also suggests that men and women differ greatly in their capacity to provide support and that the "high empathy and low withdrawal" components discussed by Pistrang and Barker may be especially challenging for men.

Most of the research in this area has focused on women with breast cancer and their male partners. The research has not specifically looked at the differences between men and women in terms of whether their different abilities to
communicate affects the psychological adjustment of both patients and spouses. As yet there have also been no attempts to evaluate an intervention to affect the patient-spouse relationship during the period of adjustment to cancer. It is these issues that the present research seeks to address.

**Hypotheses:**
1. That cancer patients, receiving an intervention designed to enhance partner support, will have lower levels of psychological distress than those who receive standard care alone.

2. That the partners of cancer patients, receiving an intervention designed to enhance partner support, will have lower levels of psychological distress than those who receive standard care alone.

3. That the intervention will improve the patient’s perception of the effectiveness, helpfulness and supportiveness of their communication with their spouse, and will lead to higher satisfaction with the relationship relative to the control group.

4. That patients’ perception of support and empathy from their partners will be associated with good psychological adjustment.

5. That males are more likely than females to perceive their spouses as their primary source of support in equivalent roles of patient or partner, and

6. That the intervention will lead more females to regard their spouses as their primary support.

7. That female patients will perceive their spouses to communicate lower empathy and supportiveness, and higher criticism and withdrawal than male patients.

**METHOD**

**Subjects**
Married or co-habiting couples, of whom one partner has first diagnosis of cancer (i.e. 50% male patients). Diagnosis within the past three months. Partner must not have had cancer themselves at any stage. Current treatment must be with the aim of cure, and the prognosis should be at least one year.
Preferably cancer site should be the same or comparable for both men and women, so that the disease or treatment does not bias the results. Colorectal would be an ideal choice since its incidence is similar between the sexes and is the second most common cancer site.

**Proposed Design and Procedure**

Randomised control trial over a 1 year period.

Patients will be recruited at first oncology out-patient appointment. They will be invited to participate in a research project to look at ways people, both patients and their spouses, cope with their diagnosis and treatment.

Patients and spouses who consent to participate, by returning their consent forms, will then be sent pre-intervention questionnaires (to be completed independently and returned separately in stamped, addressed envelopes). These questionnaires will assess:

1) Personal and demographic information (Time since diagnosis, age, class, premorbid psychiatric history, size of family, duration of relationship, etc).

2) Recent or concurrent treatment, if any (e.g. surgery, radiotherapy, chemotherapy, hormone treatments, psychological interventions.)

3) Current satisfaction with relationship (identify problems), (standardised questionnaire; such as Dyadic Adjustment Scale?)

4) Psychological functioning (HAD and SCL-Anxiety, SCL-depression and SCL-Hostility), some measure of self-esteem?

5) Patients’ perception of the level and quality of disclosure with the partner about the experience of cancer (using the same measures as used by Pistrang and Barker’s in order to compare results)

Once the pre-intervention questionnaires have been returned from the couples, the couples will be randomised to either the experimental or control arm. They will then be sent video-recordings to be watched together at home, with a brief questionnaire about how useful and relevant they found the video. They will be asked to return the videos and questionnaire to the researcher by post within one week.
Three months after watching the video, the couples will be reassessed on measures 2, 3, 4, and 5. They will also be asked to rate retrospectively the usefulness of the video. Again, questionnaires will be mailed to the subjects.

**INTERVENTION**

**Control Intervention**
The Control Group will receive a video, also to be watched by the couple together: same length and format as experimental group but using 'benign' advice. They will also be given a leaflet with the same advice as on their video.

e.g. Try having a short rest each day. Do as much as you feel able to do but don't overdo it. Take it one day at a time. Before you know it the treatment will be over. Do ask the staff if you have any questions.

**Experimental Intervention**
(A) Patient testimonies concerning partner support
(B) Bulleted written advice on screen with talk-over by ‘professional voice’.
(C) Leaflet with key bullet points reiterated as reminder for patient and spouse to keep. Both partners have their own identical leaflet.

**REFERENCES**


Cancer Research Campaign (1989) *Mortality*. Fact Sheet 3.1


POST-TRAUMATIC STRESS DISORDER AND THE DIAGNOSIS OF CANCER - A REVIEW

Introduction

Although cancer is increasingly regarded as a chronic disease by professionals, many people continue to view the diagnosis of cancer as their worst fear for, in the public's mind, cancer is equated with certain, imminent death (Weisman and Worden, 1976). It seems likely therefore that most people would regard the diagnosis of cancer as a traumatically stressful event. In the weeks and months following the diagnosis the patient and their family must cope with the varied and difficult consequences of this news, including treatment side-effects, frequent hospital visits, changes to social roles and relationships, as well as adjusting to other emotional and existential implications of this life-threatening illness (Weisman and Worden, 1976). It is perhaps little wonder that psychological disorders, particularly anxiety and depression, are common among cancer patients, with prevalence rates of between 30 and 50 per cent. (Derogatis, Morrow, Fetting et al, 1983; Brennan and Leach, 1996).

The diagnostic criteria for Posttraumatic Stress Disorder (PTSD) in the revised 3rd edition of the Diagnostic and Statistical Manual of Mental Disorders (DSMIII-R: American Psychiatric Association, 1987), specifically excluded patients with medical illnesses. Illness was not considered to be "outside the range of normal human experience" or a stressor of sufficient magnitude to produce the syndrome of PTSD. However, the diagnostic criteria for PTSD in the 4th edition of the DSM of Mental Disorders (DSM-IV: American Psychiatric Association, 1994) no longer emphasise the importance of the event itself but also consider the psychological experience of the person in the event (e.g. intense fear and helplessness.) More specifically, the definition of the traumatic event includes "being diagnosed with a life-threatening illness". Consequently, people with cancer may now be considered to be at risk for PTSD.
It is reasonable to ask whether there is sufficient empirical evidence to support the notion that the diagnosis of cancer itself can lead to PTSD. If this is the case, what steps might be taken to mitigate the trauma of the diagnosis so as to prevent the development of PTSD? This review will limit itself to adults with cancer, rather than survivors of childhood cancer.

**The Clinical Diagnosis of PTSD**

The essential feature of Posttraumatic Stress Disorder is the development of characteristic symptoms following exposure to an extreme stressor (Criterion A). The nature of this stressor involves actual or threatened death or serious injury, or other threat to one’s physical integrity or that of others (DSM-IV: American Psychiatric Association, 1994).

The three groups of characteristic symptoms in PTSD include:

**Criterion B**: repeated reliving of the trauma through intrusive memories, flashbacks or dreams, producing intense distress.

**Criterion C**: avoidance of cues which elicit memories of the trauma – these cues can be environmental or intra-psychic, e.g. a memory. Several of these features may be subsumed under the general term dissociation phenomena. Criterion C includes a “sense of a foreshortened future (e.g. does not expect to have a career, marriage, children or a normal life span)” (p.428). In cancer this is often a realistic and common concern (Weisman and Worden, 1976) but perhaps so common as to be functionally useless as a diagnostic discriminator.

**Criterion D**: increased arousal (sleep problems, irritability, poor concentration, hypervigilance and exaggerated startle response.) As will be seen below, Criterion D has rarely been systematically measured in cancer patients.
In order to meet the full diagnostic criteria of PTSD, components of these three groups of symptoms must be present for more than one month (Criterion E) and the disturbance must be seen to cause significant distress or impairment in social, occupational or other important areas of functioning (Criterion F).

**PTSD and psychological symptoms in cancer**

A number of studies have attempted to study PTSD symptomatology among cancer patients. Cordova et al (1995) assessed 55 primary breast cancer patients (stages I to III), 6 to 60 months after the end of their treatment. 71% had had a mastectomy, 29% had had a lumpectomy and most subjects had had adjuvant radiotherapy or chemotherapy. They were assessed using the Impact of Event Scale (IES) (Horowitz, 1979), the PTSD Checklist – Civilian version (PTSD-C) (Weathers, Huska and Keane, 1991), and a quality of life/general health measure.

Forty-nine per cent of subjects indicated that they experienced repeated, disturbing memories of their “experiences with cancer”, and between 5% and 10% of subjects appeared to merit a DSM-IV diagnosis of PTSD. Although this is roughly equivalent to base-rate PTSD among women in the general community (Resnick, Kilpatrick et al, 1993) the authors point out that their study limited itself to cancer-related experiences so may underestimate the prevalence of PTSD among its sample. This study is weakened by its small sample size, its retrospective nature and its exclusive use of self-report measures.

Other retrospective cross-sectional studies have reported similarly high levels of intrusion and avoidance at various intervals after active treatment has ended (Ostroff, Mashberg and Lesko, 1989; Kornblith, Anderson, Cella, et al, 1992a; Kornblith, Anderson, Cella, et al, 1992b; Kornblith, Herr, and Ofman, 1994; Greenberg, Goorin, Gebhardt et al, 1994), suggesting that psychological
reactions to diagnosis, treatment and the psychosocial consequences of the disease are highly persistent.

The effect of concurrent stress was studied by Baider and Kaplan De-Nour (1997) who surveyed three groups of early breast cancer patients an average of three years after their diagnosis. The group with concurrent stress (recent immigrants) had the highest distress on the Brief Symptom Inventory (BSI) (Derogatis and Spencer, 1982) and the highest intrusion and avoidance scores on the IES. The group with no additional stress had the lowest distress and intrusion scores, while those with a history of trauma (Holocaust survivors) fell between the other groups.

A prospective Norwegian study (Tjemsland, Søreide, and Malt, 1996a) assessed 106 consecutive female patients with early breast cancer (stage I or II) before surgery, only one or two weeks after their diagnoses, by means of a psychiatric interview, the IES, and the General Health Questionnaire-28 (Goldberg and Williams, 1988). Subjects reported high levels of intrusion and avoidance. The two highest scored items were: “I’ve had waves of strong feelings about the illness” (an intrusion item endorsed by 95% of subjects) and “I’ve felt as if the illness hadn’t happened or as if it was not real” (an avoidance item endorsed by 87% of the subjects). Levels of distress were predictably high in view of the temporal proximity to the diagnosis. There was a statistically significant association between IES intrusion and ‘casehood’ on the GHQ.

When the patients were reassessed six weeks after surgery, their traumatic stress symptoms were significantly lower (Tjemsland, Søreide, and Malt, 1996b). High scores on intrusive anxiety had dropped from 44% of subjects to 18%, and avoidance had dropped from 29% to 14%. However, half the patients reported having difficulty falling asleep because of “pictures or thoughts about the illness coming into my mind”, and half the patients admitted avoiding talking about their illness. Many patients continued to have dissociative symptoms such as feelings of unreality and numbness, or continued to have bad dreams about the
illness. On the whole, however, IES variables in the pre-surgery phase were poor predictors of the same variables six-weeks post-surgery. In summary, by the time the patients were retested, their initially high levels of anxiety and intrusion had declined dramatically, yet 8% of the sample were considered to have a possible PTSD.

Matched pairs offers a stronger design and this methodology has been pursued by a few authors. Celia and Tross (1986) compared 60 male Hodgkin’s disease survivors with 20 age-matched healthy men (acquaintances of some of the survivors). Participants had been disease-free and had received no treatment for the previous 6 to 140 months (median 24 months). Subjects were administered the BSI, a sexual functioning scale, the IES, Rosenberg’s Self-Esteem Scale (Rosenberg, 1965), and a semi-structured interview to examine global adjustment. For the IES, control subjects were asked to consider a self-specified stress (e.g. personal injury, death of spouse).

On most measures there was little difference between the two groups. However, while the survivor sample showed greater appreciation of life than controls, they also showed significantly more avoidance and intrusion. Although this study supports the general finding of increased intrusive and avoidant thinking in cancer survivors, it provided no information regarding the presence of PTSD. Furthermore, the control group was not randomly selected which may have introduced some bias in the results.

A more recent study also used matched pairs but is weakened by small numbers, being part of a PTSD field trial for DSM-IV (Alter, Pelcovitz, Axelrod, et al, 1996). Interviews were conducted with 27 randomly selected female patients, three years after their diagnosis of cancer (22 of the 27 had had breast cancer). A matched control group, demographically comparable, was identified in the community through a random-digit dialling procedure. None of the community sample had had cancer themselves. Current and lifetime PTSD was assessed using the Structured Clinical Interview for DSM-III (SCID). A diagnosis of
lifetime disorder was made when symptoms of PTSD occurred at any time more than six months prior to the interview. Psychological distress was measured using the Symptom Checklist-90 (SCL-90) (Derogatis, 1977).

None of the control group showed any indication of PTSD while among the cancer survivors, one was shown to have current PTSD and a further six met lifetime criteria for PTSD (all related to their "cancer experience"). Those with lifetime PTSD had significantly higher psychological distress scores than those not meeting PTSD criteria. In summary, those with a previous history of PTSD as a result of their cancer suffered significant continued distress three years later.

One prospective matched-pair study sheds some light on the development of anxiety and depression even though patients diagnosed with frank PTSD were excluded from the study. Brewin, Watson, McCarthy, et al (submitted for publication) compared 65 depressed and 65 non-depressed cancer patients (matched by age, sex, type of cancer, and size and spread of the disease) from a cancer outpatient department, on measures of intrusive memories of stressful life events, using the IES. The authors fail to specify the time since diagnosis and whether it was a first diagnosis. The depressed group (as defined by the HAD) were subdivided according to whether or not they met DSM-IV criteria for major depression (assessed by the SCID) into mildly depressed and severely depressed.

Prior to the analysis and in order to answer other research questions, six patients who met the diagnostic criteria for PTSD were excluded (5 severely depressed and 1 control patient). Of the remaining subjects, the researchers found that 11% of controls, 32% of mildly depressed and 43% of severely depressed reported at least one intrusive memory. Among the intrusive memories reported, 76% were clearly related to illness, injury and death (e.g. friends or relatives) and 44% were specifically related to cancer.
In a subsequent study (Brewin, Watson, McCarthy, et al, in press) the same patients were re-interviewed six months later. Due to subject attrition (mainly death) only 28 of the 35 subjects, who at baseline reported at least one intrusive memory, were re-assessed as to their continued experience of intrusive memories. Continued intrusion of the same memory was highly predictive of depression at the second time point. Also, the presence of at least one intrusive memory at baseline was associated with greater anxiety at follow-up, with greater avoidance of the memories at baseline predicting more anxiety at follow-up. The authors speculated that intrusive memories (e.g. of deaths in the past) have salience for cancer patients who are anxiously concerned about future threat (e.g. recurrence and their own death) and that by the follow-up period the protection afforded by avoidance had broken down causing more anxiety.

In view of its more bleak implications, the diagnosis of recurrent disease is arguably a more ‘severe’ traumatic event than the first diagnosis and, indeed, data from two studies suggest that it results in more traumatic symptomatology. Kaasa, Malt, Hagen, et al, (1993), studied 247 patients (46% women) with mixed-site metastatic cancer undergoing palliative radiotherapy. Subjects were given the IES, GHQ-20, and a pain questionnaire before the start of their treatment. The amount of time since diagnosis was unreported in this study and, more importantly, the authors do not specify how many of the patients were coping with a first diagnosis of cancer and how many a diagnosis of recurrence. One third of the patients scored above the “high” threshold on either the intrusion or avoidance subscales of the IES, and 21% scored high on both scales. Interestingly, in view of the fact that many, if not all the patients were probably coping with a recurrence of their illness, 65% reported feelings of unreality, as if the cancer had not happened or was not real. The authors concluded that a “substantial number” of the patients in their study appeared to be suffering with a clinical syndrome conforming to PTSD though, without data on the duration of symptoms and a specific diagnostic assessment, this claim is impossible to substantiate from the data presented.
An earlier study specifically considered disease recurrence. Celia, Mahon and Donovan (1990) recruited patients who had been disease-free for at least six months before their recurrence. 40 subjects (with mixed tumour types) were all undergoing cytotoxic chemotherapy, were considered by their physician to have at least six months to live and had been given their diagnosis of recurrence within the past 30 days. They were given the IES, the PAIS—self-report (Derogatis and Lopez, 1983), and a semi-structured interview which included a question relating to the degree to which the patient was surprised by their recurrence diagnosis.

Results indicated high levels of psychological distress, significantly higher than a demographically equivalent mixed-cancer first-diagnosis reference group. 43% scored above the cut-off (20) for intrusive symptoms while 80% scored above it for avoidant symptoms. 78% of the sample reported finding their recurrence diagnosis more upsetting than their initial diagnosis, while only 8% found their initial diagnosis more upsetting. As predicted, those patients who were "completely surprised" had significantly higher intrusion scores that those who "knew it could happen" (who did best) or who were "not at all surprised". Among those with their first recurrence (two thirds of the sample) avoidant responses were more common. Intrusive symptoms also tended to be more common in this group though this did not attain significance. All but one patient experienced a “collapse of hope” following recurrence and roughly half the sample were concerned that their physician might decide not to treat the recurrent disease. 18% believed their families would be less supportive than after their first diagnosis, and there was also a belief that health care staff were not as interested and were not providing as much support or information as they had when the patient was first diagnosed.

The authors observed that “one important component of any trauma that places a person at increased risk for later symptomatology is the extent to which the victim is surprised by the experience,” (p. 16) an observation for which there appears to be strong evidence in general trauma literature (Foa, Steketee and
Rothbaum, 1989). They conjectured that a moderate level of fear therefore may be adaptive in terms of preparing patients for the emotional impact of recurrence. However, this study is weakened both by its cross-sectional and retrospective design; in particular, those currently coping with the emotional distress of recurrence may have distorted their recall of their earlier diagnosis.

**Summary and Methodological Limitations**

These empirical studies of cancer patients suggest that psychological distress and high levels of intrusion and avoidance are common in the weeks following diagnosis (Kaasa, Malt, Hagen, et al, 1993; Tjemsland, Søreide, and Malt, 1996a; Brewin, Watson, McCarthy, et al, submitted for publication). These symptoms would likely be sufficient to meet DSM-IV criteria for PTSD were it not for their short duration and the fact that few papers have reported on physiological reactivity or arousal. However, they most likely reflect the normal processes of cognitive adjustment or, at worst, an acute stress disorder, rather than constituting the pathological symptoms of PTSD. Indeed, symptoms of PTSD may only differ from normal reactions in terms of their duration; the time at which assessments are made is therefore crucial (Passik, 1994).

Over the course of the ensuing weeks and months it appears that distress, intrusion and avoidance symptoms decline quite rapidly for the majority of patients (Tjemsland, Søreide, and Malt, 1996b), consistent with other types of trauma. However, although there is wide variation in the time of assessment among the studies reviewed, and while most of them are retrospective in design, there is a consensus indicating persistent PTSD-like symptoms among a minority of patients months or even years after diagnosis and the cessation of treatment (Baider and Kaplan De-Nour, 1997; Ostroff, Mashberg and Lesko, 1989; Kornblith, Anderson, Cella, et al, 1992a, 1992b; Kornblith, Herr, and Ofman, 1994; Cella and Tross, 1986; Alter et al, 1996). Furthermore, a few authors have concluded that a diagnosis of PTSD may sometimes be warranted (Alter et al, 1996; Brewin, Watson, McCarthy, et al, in press;

More prospective studies are needed in order to chart the course of these symptoms and disentangle key predictive variables. However, a difficulty in this field is defining when the trauma threat has passed, in view of the very real ongoing threat of disease recurrence. Some authors have questioned the utility of relating the trauma of illness to a psychiatric diagnosis at all, arguing that understanding how aspects of illness and treatment remain traumatic stressors years later is the more interesting question (Kazak, Stuber, Barakat and Meeske, 1996).

DSM-IV notes that severity, duration and proximity of an individual’s exposure to the traumatic event are the most important factors affecting the likelihood of developing PTSD. In this regard, the data available among cancer patients is equivocal. Severity of disease was generally assessed by its clinical staging alone rather than also through its appraisal by patients, the latter criterion being emphasised by DSM-IV. Cella and Tross, (1986) reported evidence that both severity of disease at diagnosis and short interval since cessation of treatment predicted increased PTSD symptoms and Kaasa et al (1993) found poor performance status (i.e. physical capability) also predicted PTSD, a finding supported by other studies (Kornblith, Herr, and Ofman, 1994). However, other authors reported no such relationships (Cordova et al, 1995; Alter, et al, 1996). More aggressive treatments were also not found to predict PTSD symptomatology (Cordova et al, 1995), lending further support for the view that the major trauma of cancer is not the treatment but, more likely, the diagnosis.

Intrusive memories and avoidance are not sufficient in differentiating adaptive trauma-related distress from the presence of PTSD; an assessment of physiological reactivity or arousal is also necessary (Ehlers and Steil, 1995) yet few authors have reported data on these symptoms. Although people with cancer may develop heightened arousal, anxiety, nausea and vomiting, in
response to certain treatments (e.g. cytotoxic chemotherapy) (Redd, Dadds et al, 1993), it is doubtful that these conditioned responses are the result of trauma since the patient is expecting the treatment and it is rarely perceived as life-threatening.

Most of the studies reviewed above have used the IES alone to measure PTSD symptoms though this scale is not sufficient for the assessment of PTSD (Passik, 1994). Recent theoretical work (Brewin, Dalgleish and Joseph, 1996) has questioned the use of this scale, suggesting that it fails to capture the distinction between verbally accessible knowledge (i.e., conscious memory of the trauma) and situationally accessible knowledge (nonconscious representations of the trauma). This work also suggests that studies may underestimate levels of PTSD owing to their failure to identify subjects who may have prematurely inhibited active emotional processing.

**Theoretical Implications**

Cognitive and psychodynamic models of posttraumatic stress indicate that avoidance is a normal temporary defence or coping response to an overwhelming and distressing event (the trauma) which the individual is struggling to integrate with their existing cognitive world views or schema (Horowitz, 1986). According to these models, it is the individual's internal schema or assumptive world which enables them to predict and negotiate the social and material world. Intrusion and avoidance work at opposite ends of a control system that regulates the absorption of new information. In this sense, avoidance can be seen as an activity which impedes emotional processing while intrusive reexperiencing serves the process of integration (Ehlers and Steil, 1995). When regarded as a coping mechanism, avoidance titrates the absorption of traumatic information while denial may act as a more extreme form of avoidance, permitting no absorption.

However, as researchers in other areas of trauma have observed, the relationship between intrusion and avoidance is not straightforward and little is
known about their roles in determining later affective and arousal symptoms (Joseph, Yule and Williams, 1995). Brewin, Watson, McCarthy, et al (1998, in press) found that later anxiety could be predicted by the extent to which cancer patients with intrusive memories attempted to avoid these memories. The significance of intrusive memories for cancer patients therefore may be more to do with ongoing threat than past loss, and it is the breakdown of avoidance mechanisms that provokes more anxiety. Ehlers and Steil (1995) have stated that, in other traumas, negative interpretations of intrusive thoughts may lead to a sense of ongoing threat. They argue that the patient interprets the fact that they are experiencing intrusive thoughts as further evidence of prior maladaptive beliefs (e.g. "I have a brain injury"). This is distinct, however, from the trauma of cancer in which intrusive thoughts about the diagnosis and illness simply elicit the patient's belief that they now have cancer and may die from it; it is doubtful that patients appraise their intrusions per se as evidence of disease progression.

One survey of over 600 cancer patients in remission found that the most commonly identified cancer-related concern was fear or uncertainty about the future (Dunkel-Schetter, Feinstein, Taylor and Falke, 1992). Yet, surprisingly, the concept of future threat in cancer has not been widely examined. A paradoxical rise in anxiety has been noted at the end of treatment as the individual faces an uncertain future without frequent contact with medical services (Holland, Rowland, Leovits and Rusalem, 1979). A cancer diagnosis poses a future threat that is shaped by the individual's idiosyncratic belief system about the course of cancer (Cella and Tross, 1987), and accurate, timely and accessible information may go some way towards correcting misconceptions about this issue (Fallowfield, 1993). It may be that the individual's perception of their prognosis (i.e. the future threat) would be a more accurate measure of the traumatic impact of the diagnosis, rather than prognoses made by doctors based on clinical staging of the disease. No study has yet specifically examined this issue. However, those with a diagnosis of recurrence are more likely to have negative beliefs about their prognosis and, indeed, as this review has shown, this
group of patients do appear to have much higher intrusion and avoidance scores (Kaasa, Malt, Hagen et al, 1993; Cella, Mahon and Donovan; 1990).

An alternative formulation would be to regard intrusive and avoidance phenomena in cancer as a special form of obsessive-compulsive disorder (OCD) since there are useful parallels (Ehlers and Steil, 1995). In OCD, patients’ intrusive thoughts often centre on catastrophes that have yet to happen yet over which they idiosyncratically believe they may have some control. It is the presence of these intrusive thoughts that leads to distress and subsequent avoidance of the thoughts through compulsive neutralising activities (Salkovskis, 1985). However, while cancer patients often have intrusive catastrophic thoughts of the future (e.g. images of dying, grief-stricken relatives etc.) there is little evidence, with the exception perhaps of “bargaining” (Kübler-Ross, 1970), that they show elevated levels of neutralising activity.

Cancer itself is not a discrete stressor yet researchers have tended to use cross-sectional designs to ask cancer patients in remission to rate retrospectively the impact of their “cancer experience” as a global entity. Few studies have attempted to disentangle the various components of the disease that might be appraised as traumatic (e.g. diagnosis, hospitalisation, chemotherapy etc.) and most studies have failed to examine the particular trauma of the diagnosis to which DSM-IV specifically alludes. Thus, the existing literature leaves open the question as to whether the primary source of trauma in cancer is the diagnosis, the treatment which follows, or some other factor. While this question remains unanswered, there are grounds for believing that the process of diagnosis is critically important in mitigating the traumatic effects of the bad news. For example, in one study (Manuel, Roth, Keefe and Brantley, 1987) 35 patients with head and neck cancer were asked to complete the SCL-90 and IES three days after diagnosis, four to six weeks later (often coinciding with active treatment) and two to three months after initial diagnosis. Results indicated that diagnosis was associated with the highest levels of anxiety and avoidance of the
three time points, and that active treatment was associated with *relief* from stress-related symptoms.

**Breaking the News of Cancer**

A recent review (Ptacek and Eberhardt, 1996) of 67 medical papers on the breaking of bad news, published since 1985, concluded that while there is much clinical opinion expressed in the literature there is rarely any theoretical justification or empirical validation. It is also almost exclusively written from the clinician’s perspective which may fail to recognise the factors which minimise or exacerbate the patient’s distress. Some authors have argued that the enormity of the news that doctors must deliver may dwarf the issue of the way in which it is conveyed (Persaud, 1993). However, when integrated with the aforementioned studies on PTSD symptoms, published work in this field leaves room for optimism that certain factors may help to minimise the traumatic impact of bad news interviews. The behaviour of health care professionals during the process of the diagnosis helps to set the tone for subsequent coping (Frank-Stromberg et al, 1984)

a.) **Provide a warning shot** (Ptacek and Eberhardt, 1996; Buckman, 1998; Faulkner, Maguire, and Regnard, 1994). Breaking bad news should be seen as a process which occurs over time, rather than an event, and an early indication that difficult information is about to be conveyed may help prepare the individual (Buckman, 1998).

Most authors agree that a core component for the development of PTSD is the unexpectedness of the traumatic event (Ehlers and Steil, 1995). If an individual’s cognitive resources are entirely unprepared for bad news they are likely to be overwhelmed by it and avoidance and intrusion symptoms are more likely. Cella et al (1990) have shown that those who were “completely surprised” by their diagnosis of recurrence had significantly higher intrusion scores than those who “knew it could happen”.

Correspondingly, Tjemsland, Søreide, and Malt (1996b) have suggested that women with a close relative with breast cancer may be more emotionally prepared for the possibility of getting cancer themselves and may have learned that it is possible to survive the disease with a reasonable quality of life. Initial acceptance of the diagnosis has been associated in other studies with a family history of cancer (Frank-Stromberg, Wright, Segalla and Diekmann, 1984).

A further study which offers indirect support for giving patients time to prepare for their diagnosis found that at eight weeks follow-up, women with breast malignancies attending a ‘one-stop’ (same day) clinic had significantly higher levels of depression than women attending the traditional two-stop clinic in which patients must wait several days for their diagnosis (Harcourt Ambler, Rumsey and Cawthorn, 1997). The use of an ‘advocacy’ style of nurse counsellor intervention, in which the nurse prepares the patient for the diagnostic consultation with the physician, offers promise in this regard. Using this approach, the nurse helps patients develop a list of questions they would like to ask, whatever the diagnosis, thereby preparing the patients’ for possible bad news. However, so far support for this model is equivocal (Ambler, Rumsey, Harcourt et al., 1997).

b.) **Allow patients to control the amount of information conveyed to them** over time, and provide as much information about the diagnosis and treatment as the patient requires. The diagnosis of cancer often elicits inaccurate, often catastrophic beliefs of impending death and a perceived sudden loss of control. Foa and colleagues have argued that what distinguishes PTSD from other anxiety disorders is that the trauma has violated basic concepts of safety; the world suddenly becomes less predictable and controllable (Foa, Steketee and Rothbaum, 1989). Effective emotional processing of a trauma requires the absorption of new information (Ehlers and Steil, 1995). Factual information may therefore mitigate the traumatic impact of the diagnosis by correcting misconceptions.
about the disease and its prognosis, increasing a sense of control, safety and predictability, thereby reducing its perceived threat (Ptacek and Eberhardt, 1996). Perceived control is also thought to be essential to the maintenance of non-depressed mood (Taylor and Brown, 1988). Denial and avoidance are likely to work against this process.

However, the importance of providing adequate information at the point of diagnosis is complex. One study of breast cancer patients indicated that although patients who felt well-informed about their diagnosis and treatment experienced less anxiety and depression at one year follow-up than those who felt inadequately informed, most women acknowledged that they had been too shocked on hearing the word ‘cancer’ to absorb much of the rest of the interview (Fallowfield, Baum and Maguire, 1986).

The use of tape-recordings of medical consultations appears to improve patient retention of information and facilitates patients’ requests for clarification (Ford, Fallowfield, Hall and Lewis, 1995) but does not appear to reduce psychological morbidity (McHugh, Lewis, Ford et al, 1995). Over the course of their illness and its treatment, however, many patients report that their need for information changes (Blumberg, Kerns and Lewis, 1983) and what may be important is that easy access to information enhances a patient’s sense of control and safety in their uncertain situation.

c.) **Identify support network and encourage emotional processing.** Many authors have commented on the importance of enhancing social support through (i) encouraging patients to invite someone supportive to their diagnostic interview, (ii) working with the patient to identify further sources of support, and (iii) encouraging patients to regard their physician as an additional support resource (Ptacek and Eberhardt, 1996). Lack of social support, especially partner support, was found to be a significant risk factor for the development of PTSD symptoms (Tjemsland, Søreide, and Malt, 1996b), consistent with research on other sources of PTSD (Ehlers and Steil,
1995; Jones and Barlow, 1990). Lack of social support is also a significant risk factor for the development of psychological disorders in cancer patients (Rowland, 1990). The availability of good social support is associated with complete and successful processing of trauma (Brewin, Dalgleish and Joseph, 1996) possibly because it allows victims to reappraise the cause of the event as external and not attributable to their own actions (Joseph, Brewin, Yule and Williams, 1991), or by correcting maladaptive interpretations of the trauma (Ehlers and Steil, 1995). Pennebaker (1993) has shown that even simply writing about the trauma may help people assimilate it into new more elaborate schemata. In view of the study by Cella et al (1990), described above, it is especially important to ensure that those facing a diagnosis of recurrence have adequate support from both family members and professionals.

d.) **Retain a clear sense of hope**, even when the prognosis is poor. Believing that one's situation retains some element of hope appears to be essential for cognitive adaptation (Weisman and Worden, 1976; Carver, Pozo, Harris, et al, 1993). Cella et al (1990) noted that “the central organising theme with respect to the impact of recurrence seems to be the loss of hope” (p. 20). All but one of the 40 patients in their study acknowledged that they felt less hope at recurrence than they had at first diagnosis. In one Scandinavian study (Boland, 1985), the highest incidence of suicide was found in cancer patients who had been offered no further treatment and no further contact with the health care system.

e.) **Encourage active collaboration.** Construing oneself as actively engaging in cancer prevention, such as continuing to take tamoxifen (Alter et al, 1996), appears to be a common and adaptive coping mechanism (Taylor, 1983). Many patients want to participate in the fight against their cancer and often do so by turning to complementary therapists who offer a level of active collaboration that is absent in conventional medical settings (Sheard, 1994). Active coping among cancer patients has been positively associated
with optimism and acceptance of the disease (Carver, Pozo, Harris, et al, 1993) and the time of diagnosis could therefore be used as an opportunity to engage the patient in the use of such active coping mechanisms (e.g. health education advice on healthy eating, stress management, exercise etc.) Although studies have reported that not all patients want to be active collaborators in their treatment (Degner and Sloan, 1992), it remains likely that many patients wish to create a discontinuity with their pre-cancer lifestyles (Taylor, 1983).

**Conclusions**

Whether or not cancer patients commonly merit the full diagnosis of PTSD, there is growing evidence that a significant minority develop many of the key symptoms of the syndrome, particularly cognitive intrusion and avoidance, and psychological distress. What has not been adequately documented among cancer patients is the prolonged physiological arousal that is a necessary criterion for the diagnosis PTSD. Furthermore, with a few exceptions, the studies reviewed have largely failed to specify the cancer diagnosis as the primary traumatic event and have tended to measure responses to cancer as a global entity. More prospective longitudinal studies focusing on the traumatic effects of diagnosis are needed to disentangle the normal processes of cognitive adjustment from longer-term symptoms of PTSD. If the diagnosis of cancer can be reliably shown to be the source of post-traumatic symptomatology, an obvious further question will be whether PTSD treatments that have been found to be effective in general trauma are also efficacious in cancer. In the meantime, experimental and theoretical work to date offers a number of clues as to how the process of delivering bad news may be refined in order to mitigate its traumatic impact.
References


INTRODUCTION

Surveys of psychological disorders among cancer patients have found prevalence rates of between 30 and 50 per cent for anxiety and depression (Derogatis, Morrow, Fetting et al, 1983; Brennan and Leach, 1996). The term 'adjustment' has come to be used in the cancer and health psychology literature to denote the absence of such psychological morbidity, and a return to pre-morbid functioning. It is therefore not surprising that 'psychological adjustment' is an important concept in research into chronic illness (Hatchett, Friend, Symister and Wadhwa, 1997).

As a result of this appropriate concern with psychological morbidity there has been a preoccupation in the field of psycho-oncology with the prediction and early detection of affective disorders (through screening measures and improved communication skills of health professionals), as well as with the efficacy of therapeutic interventions (Maguire, 1995). However, social psychiatry is only one approach to prevention in this area. Another is to develop an understanding of the psychological processes involved in coping with the implications of cancer, and then to test ways of mitigating their impact so as to prevent the psychological disorders with which cancer is so commonly associated. Yet within psychosocial oncology literature, theoretical models of adjustment have rarely been articulated from which testable predictions can be made about the development of psychological disorders, nor about steps that might be taken to prevent them.

Without adequate definition and theoretical underpinning, use of the term adjustment may be vague and misleading. The term 'adjustment' suggests the completion of change from one state to another, and research has often focused...
on adjustment as if it were merely the end-point of coping with the global threat of cancer; indeed, "poor adjustment" is sometimes used to denote psychological morbidity. The patient's medical condition, especially the presence or absence of unpleasant symptoms like pain and the side-effects of treatment, such as fatigue, nausea and vomiting (Rodrique, Behen and Tumlin, 1994), as well as more advanced illness (Bukberg et al, 1984), are highly associated with poor psychological functioning but it is questionable whether morbidity caused in this way should be equated with "poor adjustment". Confusion is further compounded by use of the psychiatric diagnosis of adjustment disorder which describes "significant emotional or behavioral symptoms in response to an identifiable psychosocial stressor or stressors." (DSM-IV: American Psychiatric Association, 1994.) Again, it is arguable whether psychological turmoil provoked by a life event should be regarded as morbid or part of the adaptive process.

Rather than viewing adjustment as an end-state, it may be more fruitful to ask: what are the components of a normal "adjustment" to cancer, what is it that is being 'adjusted', and what processes are involved? It is the purpose of this paper to review the concept of adjustment as a psychological/developmental process and to suggest theoretical links between this process and the development of psychological disorders in cancer, offering a number of hypotheses for preventing these disorders. Finally, the paper will consider the relationship between the concepts of adjustment and quality of life.

**Problems of Definition**

The concept of adjustment originates from the Darwinian notion of "adaptation" which posits that those species most fitted to adapt to the dangers of the physical world are most likely to survive (Moos, 1986). Watson and colleagues (Watson, Greer, Young, et al, 1988) have defined adjustment to cancer as "the cognitive and behavioural responses the patient makes to the diagnosis of cancer" (p.203). This narrow definition of the term fails to include other important aspects, including the social and spiritual dimensions of
adaptation, responses to stressful events following diagnosis such as treatment and discharge, and any indication of what constitutes a healthy or successful adjustment. An earlier more encompassing and satisfactory definition suggests that “adjustment consists of the psychological processes by means of which the individual manages or copes with various demands or pressures” (Lazarus, 1969, p.18.)

The diagnosis of cancer and its aftermath undoubtedly leads to major life changes in a significant proportion of people, though these changes are not always negative and it is not clear that they are detected by the more commonly used outcome measures within psychosocial oncology (e.g. Hospital Anxiety and Depression (HAD) scale [Zigmond and Snaith, 1983], Profile of Mood States [Lorr and McNair, 1984], etc.). For example, in one survey of 200 cancer survivors, 30% had changed jobs and 23% had changed their living arrangements in the two years since their treatment (Stalker, Johnson and Cimma, 1990). While levels of anxiety and depression may return to premorbid levels, rarely does a cancer patient describe a sense of continuity with their lives before cancer — there is invariably a shift in the individual’s sense of themselves and the world (Janoff-Bulman, 1992; Taylor, 1983).

**Adjustment as a process of adaptation to change**

Rather than viewing adjustment as the attainment of a normatively-derived emotional state (e.g. a particular threshold on the HAD), it might be clearer to reserve the term to describe the process of adaptation that people make to changed circumstances in their lives. This broader and more neutral definition emphasises a more psychological and developmental approach. The process has been conceptualised in a number of ways. Social-cognitive theorists have examined the nature of the adaptation from one state to another and the psychological tasks facing the individual. They have focused on adjustment as a goal or journey that individuals strive to negotiate. Coping theorists (e.g. Lazarus and Folman, 1984; Nerenz and Leventhal, 1983), by contrast, have focused on the strategies or vehicles that people employ to negotiate the
adjustment journey and mitigate the negative emotions generated by the change or threat. It will be argued that both these inter-related approaches offer the field of psycho-oncology useful models with which to understand the processes of adjustment and to prevent later psychological and social problems.

**Coping**

According to coping theory (Lazarus and Folkman, 1984), coping is the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual. It is an interaction between the individual and the environment in which each affects the other.

Coping research in cancer has largely examined relationships between coping responses and psychological outcomes (Parle, Jones and Maguire, 1996) though these studies have mostly used cross-sectional designs and employed self-report measures of coping responses to recent stresses. Lazarus (1993) has pointed out that, because of the diverse threats that people with cancer may be dealing with at any moment, research on the coping process must specify “the particular threats of immediate concern to the patient and to treat them separately rather than broadening the focus of attention to the overall illness” (p. 236). He has made a distinction between research focusing on a person’s coping style, a general propensity to deal with stress in a particular way, and that focusing on elements of the coping process. Both approaches are important and both are evident in the psycho-oncology literature.

The diagnosis, treatment and aftermath of cancer involves a long process of adaptation to multiple threats and novel experiences. How an individual characteristically appraises and responds to these threats and experiences is known as their coping style. The implicit assumption of the coping style approach is that coping will reflect a relatively enduring attitudinal/behavioural style, similar to a personality trait.
Watson has used the term “mental adjustment” to denote the coping style of individuals in the face of a diagnosis of cancer (Watson, et al, 1988). Watson et al (1988) developed the Mental Adjustment to Cancer (MAC) scale which identifies five behavioural styles of coping: denial/avoidance, fighting spirit, fatalism, helplessness/hopelessness, and anxious preoccupation. They found that the last three coping styles were significantly associated with depression as measured by the Hospital Anxiety and Depression scale which was simultaneously administered. They also reported that the response of “fighting spirit” was significantly associated with less psychological distress (Watson, et al, 1991) and found a similar positive association with the response of denial (Watson, Greer, Blake and Shrapnell, 1984), though this was not replicated in their later studies.

In a prospective study (Carver, Pozo, Harris, et al, 1993) of 59 early stage breast cancer patients, optimism was measured initially and coping (COPE) and distress (POMS) were assessed repeatedly around the time of surgery and again up to 12 months post-surgery. The results indicated that optimism was inversely related to distress at each assessment point, but positively related to active coping efforts, and acceptance of the reality of the disease. This suggests that optimism may be a personality trait which is associated with the use of certain coping behaviours. This study reported that denial correlated with higher distress, opposite to the early findings reported by Watson et al (1984). The authors speculated that acceptance of the situation is important for adjusting to it when the situation, like cancer, has to be endured. This view is consistent with bereavement literature which indicates that denial is a “temporary solution” which, if it persists, can lead to later maladaptive adjustment (Parkes, 1988).

The coping style approach has led to some fruitful clinical research (Moorey, Greer, Watson et al, 1994) in which patients’ underlying schemata have been altered (leading to the reduction of helplessness and an increase in fighting spirit) through the use of Adjuvant Psychological Therapy (APT) (Moorey and Greer,
1989), a form of cognitive-behavioural therapy adapted for use with cancer patients. However, a recent study on testicular cancer patients has failed to support the efficacy of APT in this particular group (Moynihan, 1998).

The coping style approach is limited by the concept of coping leading to consistent behavioural responses by the individual rather than as a situation-specific variable which may change over time in the light of different stresses. There is some evidence (Folkman, Lazarus, Gruen and De Longis, 1986) to support the idea that problem-focused coping is more responsive to the nature of the stressful context, while emotion-focused coping is more influenced by personal factors, but this work has not been conducted with respect to the specific stresses of cancer. In cancer, the appraisal of threat is likely to vary according to the stage of the disease and its treatment. For example, anxious preoccupation may not characterise an individual while undergoing their treatment, though it may be a significant feature of their behaviour prior to a hospital follow-up appointment.

Lazarus (1993) has emphasised the importance of appraisal variables though these have been rarely examined in the field of cancer. One exception to this was a study by Parle, Jones and Maguire (1996) which sought to assess the role that coping in the first few weeks after diagnosis had in the later development of affective disorders. They prospectively studied 673 newly diagnosed cancer patients to assess the effects of their appraisals, coping responses and resolution of 14 specific concerns to do with their cancer (as measured using a semi-structured interview) on subsequent mental health (as measured by the Psychiatric Assessment Schedule). They found that neither the nature of the patients' concerns, nor any specific coping response, predicted the development of an affective disorder. However, they did find that those who had high levels of generalised worry and multiple concerns were subsequently more likely to feel helpless and do nothing in response to these concerns.
The finding that helplessness, which may be regarded as a negative secondary appraisal (i.e. a belief that one does not have the resources to cope with a particular threat), was predictive of affective disorders is consistent with Watson et al's (1991) data though, because of the cross-sectional design of this earlier study, it was not apparent whether helplessness was a result of dysphoria or whether the reverse was true. The Parle, Jones and Maguire data suggest that “adaptive copers hold outcome expectancies and self-efficacy beliefs that are likely to facilitate their performance of coping responses” (p. 743).

A number of studies of cancer patients have reported cross-sectional data to support the idea that coping strategies characterised by avoidance or acceptance-resignation are associated with poor psychological adjustment (Dunkel-Schetter, Feinstein, Taylor and Falke, 1992) while active coping responses are associated with good outcome (Rodrigue, Behen and Tumlin, 1994). In one prospective study, Manuel, Roth, Keefe et al (1987) found that patients using high-approach strategies (e.g. spending a lot of time thinking about the implications of the illness) and those using high-avoidance strategies (e.g. distracting themselves by minimising the importance of the illness and getting on with other activities) reported less distress than those who were passive and made few attempts to actively cope with their disease.

The beneficial effects of active coping is reinforced by Dodds et al (1994) who proposed a model of adjustment in which two interrelated superordinate constructs are involved in the concept of the self. ‘Self as agent’ denotes a sense of personal control and a feeling that one is able to be successful at future tasks (self-efficacy), while ‘self-worth’ involves self-esteem and the absence of anxiety and depression. Using structural modelling techniques, this model was compared with other models based on data from the Nottingham Adjustment Scale which was given to 469 blind clients still adjusting to the loss of their sight at a rehabilitation centre. The authors found that acceptance and adjustment were strongly related to ‘self as agent’ but only weakly to ‘self-worth’. All these studies suggest that interventions that promote increased self-efficacy and enable
people with cancer to take control of, and participate in their lives again, are likely to help restore their confidence and self-esteem.

**Adjustment as Psychosocial Transition**

Social-cognitive theorists are concerned with the nature of the change in individuals when they are confronted with a novel experience. Unlike coping theorists who focus on how people respond to a crisis, social-cognitive theorists are interested in what is required of an individual in such circumstances though, confusingly, coping theorists often subsume “cognitive adjustment” under the rubric “emotion-focused coping” (e.g. Broadstock and Borland, 1998). It could be argued that social-cognitive theorists attempt to define the context or agenda for coping efforts.

Parkes (1971) used the term “psychosocial transition” to describe the necessary change in a person’s “assumptive world” when confronted by a critical life event such as bereavement (Parkes, 1988). Such events may have emotional, material, psychological or existential implications for a person’s *life space* (Lewin, 1935), or that part of the environment with which the individual interacts. The “assumptive world” is the result of the total accumulation of an individual’s life experience. It allows people to classify and predict the world around them in order to safely negotiate it and satisfy their needs. The concept of the assumptive world is similar to that of cognitive schema (Neisser, 1967). Since a person’s life space is continuously changing from moment to moment, so too is their assumptive world being confirmed or disconfirmed, reinforced or altered in a continuous process of elaboration, refinement and adjustment.

Small unexpected changes in life space require only small modifications in the assumptive world. However, more profound changes, e.g. psychologically threatening events (such as a cancer diagnosis), are thought to overwhelm temporarily the capacity of the assumptive world to predict or react adaptively to prevailing circumstances. Such disorientation can be seen in the period
immediately following a life-threatening diagnosis: information is hard to process and for hours, often days, the individual struggles to accept what he or she has been told. According to Horowitz (1986) there follows a psychological need to integrate the new information with existing schemata, termed the 'completion tendency' (manifested as re-experiencing the event or having intrusive memories of it), which is thwarted by a competing need to defend the mind from the full impact of the information (i.e. avoidance or denial).

This approach complements the foregoing discussion regarding active vs. passive coping strategies: "In the early stages of a trauma, avoidance can reduce stress and anxiety while allowing for a gradual recognition of the threat; later, only approach [sic] will allow for the assimilation and resolution of threat and trauma into an integrated self-structure" (Manuel et al, 1987, p.150).
Successful adjustment thus involves the individual adaptively assimilating (merging new information into existing assumptions) or accommodating change (modifying existing assumptions about the world to be able to incorporate the new information) (Piaget, 1952).

Inherent in this model, which has been elaborated by others (Moos, 1986; Janoff-Bulman, 1985, 1992), is the notion that every new experience, whether appraised as positive or negative, pleasant or unpleasant, involves the certainty that people will either "creatively reformulate" (or reappraise) the experience or modify their assumptions about the world in order to accommodate it. In most situations both processes are operating. In the case of overwhelming life events, like receiving a cancer diagnosis, it is often the individual's most fundamental assumptions that are at stake and require change. However, this process of accommodation involves huge amounts of cognitive processing, particularly since human information processing is biased towards cognitive conservatism and a tendency to maintain existing schema or deeply-held assumptions (Janoff-Bulman, 1992).
Both the life event itself and the subsequent intra-psychic changes in the individual will have consequences for members of the individual’s social network. These processes of intra-personal and inter-personal change are likely to produce emotions associated with stress, such as anxiety and dysphoria, and concomitant resistance to change such as denial and avoidance (Parkes, 1971; Janoff-Bulmann, 1992).

Changes to life space may lead to helpful and adaptive changes to, or confirmations of, the assumptive world in as far as these adjustments or confirmations allow people to interact more effectively in the social and material world. This is often experienced and described as “healthy personal growth”. On the other hand, events can also lead to maladaptive and unhelpful adjustments to the assumptive world (e.g. a sense of helplessness), or the confirmation of existing maladaptive assumptions (e.g. a sense of guilt), and this can lead to further distress and formal ‘disorders’.

This developmental view of adjustment has the advantage of being able to account for the otherwise paradoxical finding that many cancer patients describe their illness as having had a positive impact on their lives. A further advantage of this approach is that it can generate testable predictions about which assumptions are commonly undermined (or confirmed) by which specific threats (Janoff-Bulman, 1992), and what factors are likely to facilitate or hinder their reconstruction. For example, assumptions that are held with extreme confidence and have not been challenged are more likely to be “shattered” with devastating results for the victim (Janoff-Bulmann, 1985). Moreover, one might hypothesise that changes in the assumptive world are made ever harder as the disease develops because of diminishing periods of time in which to effect a revision of one’s assumptive world. It is therefore little wonder that depression is more common in the terminally ill (Breitbart, Chochinov and Passik, 1998).

A number of authors have attempted to describe the task of adjustment in terms of the resolution of threats or incongruences with existing assumptions about
the world. There is a degree of consensus among their conclusions. Cohn and Lazarus (1979) have postulated that illness entails a number of threats involving uncertainty to which the individual must respond. These include threats to (a) life; (b) bodily integrity and comfort; (c) self-concept and future plans; (d) emotional equilibrium as a result of the other threats; (e) social roles and activities; and (f) threats involving the need to adjust to new social or physical environments. Very similar constructs are described by Moos and Schaefer (1984).

Moorey and Greer (1989) conceptualised the stress of cancer along two dimensions: threat to survival ("our sense of mortality is shattered") and threat to the self-image (mental and physical abilities, personal and social roles, and physical appearance). Janoff-Bulman (1992) takes a similar view when she writes that, at the core of the assumptive world, are abstract beliefs about self, the external world and the relationship between the two. "Extreme life events", such as having cancer, shatter the assumptions that (a) the world is benevolent; (b) the world is meaningful; and (c) the self is worthy.

Taylor (1983) proposes a theory of cognitive adaptation which is essentially a similar conceptualisation of adjustment to the authors above. However, Taylor's theory proposes certain emotion-focused coping strategies which function to restore schema which she postulates are illusions that are characteristic of positive mental health. She maintains that normal human thought involves overly positive self-evaluations, exaggerated perceptions of control or mastery and unrealistic optimism (Taylor and Brown, 1988). The theory was derived on the basis of extensive interviews with 78 breast cancer patients who appeared to (a) search for a meaning for their predicament (finding a causal explanation for their cancer and restructuring the priorities of their lives as a result of their cancer); (b) gain a sense of mastery (believing that they could exert control over the course of their cancer; for example, believing that they had changed from the way they lived their lives before their diagnosis); and (c) enhance the self
(through construing personal benefit from the illness or comparing themselves with others worse off).

While sound and plausible from a clinical and intuitive perspective, these conceptualisations largely fail to account for why people negotiating these changes appear to be vulnerable to the development of psychological disorders and other forms of distress. However, it is possible to synthesise three recurring themes from the work of social-cognitive theorists, each of which offer testable hypotheses for the prevention of psychosocial problems.

**LOSS OF CONTROL**

The diagnosis of cancer rapidly leads to fundamental changes in the relationship between the individual and their environment. Together with the perceived loss of control over the body (the prospect of having to accommodate changes to its appearance, capabilities and sensation), new cancer patients are suddenly faced with high levels of uncertainty (the possibility/probability of their death) and novelty (the complex medical environment) over which they perceive they can exert little control. Attachment theory (Bowlby, 1979) predicts that in situations of novelty, ambiguity and fear people are likely to regress to more infantile ways of behaving. In particular, they are likely to welcome any benign figure of authority who provides safety by appearing to be in control of the situation. Thus, like denial, regression may serve to provide a temporary defence at times when the assumptive world is unable to negotiate and predict prevailing reality. Crisis theory (Moos, 1986) endorses the idea that people are especially receptive to outside influences at times of change and uncertainty.

Over the course of their illness, many people choose to collaborate more closely with their doctors and become better informed about their treatment and, as Taylor (1983) has observed, many people prefer to contribute actively to their treatment (e.g., 49% of her sample had changed their diet, believing that this would prevent recurrence). Furthermore, evidence from studies on coping, cited
above, suggest that active coping and “self-as-agent” lead to self-efficacy and enhanced control.

Many theorists agree that a sense of personal control, whether illusory or not, is integral to the individual’s self-concept and self-esteem, as well as the maintenance of non-depressed mood (Taylor and Brown, 1988). The corollary of this is that measures to encourage cancer patients to resume as much control as they wish, over all aspects of their lives (including their treatment), is likely to have a beneficial effect on mood and may serve to prevent depression. On the one hand, people with cancer could be encouraged to assimilate or reappraise their perceived loss of control by the active coping response of reassuming control in some areas of their lives. At the same time, assumptions about control would gradually need to accommodate the fact that one may die sooner than expected, an event over which one has, indeed, limited control.

LOSS OF ENGAGEMENT

Much of a person’s sense of themselves, or their identity, is derived from a personal trajectory which offers goals and rewards in the future. Goals may be short-term and clear-cut (e.g. looking forward to meeting friends for lunch later this morning) to long-term and more abstract (e.g. one day writing a novel). In all aspects of life, goals and rewards provide structure and motivation. Without significant motivational structure in our lives we are in danger of feeling that life is pointless; apathy and a sense of helplessness can set in, and we are at risk of depression (Beck, 1967). Such a situation can occur, for example, in the context of long-term unemployment (Dew, Bromet and Penkower, 1992).

A life-threatening diagnosis, by definition, confronts the individual with his or her mortality. Almost regardless of the actual prognosis that has been given, many people begin to prepare for the possibility of their death (Weisman and Worden, 1976). Implicit long-standing life goals may suddenly become clear and distinct yet, at the same time, their eventual attainment may seem unlikely and unrealistic. Other goals may be dismissed as trivial and no longer
important, while a number of people report that their illness helped them develop entirely new motivational priorities (Taylor, 1983).

Serious illnesses threaten the individual's motivational framework which becomes in danger of breaking down. In cancer, the demands of months of radiotherapy and/or chemotherapy can lead the patient to feel dislocated, as they feel less and less engaged in their work and social lives. Life becomes dominated by treatment-related rituals (e.g. daily visits to the radiotherapy unit), and the side-effects of treatment (nausea, fatigue etc.) preclude the hope that one might fully enjoy an event or achieve something useful. Such events may lead to maladaptive assumptions about the world. Nerenz and Leventhal (1983) have described the contrast between individuals whose lives are entirely dominated by their disease and those who are able to "encapsulate" their disease, otherwise try to function normally, and regard it as only one component of the self. Some cancer patients appear to engage in what has been termed "defensive pessimism" (Norem and Cantor, 1986) by failing to make plans for the future lest they be disappointed (e.g. by a recurrence of their illness).

Beliefs in personal efficacy are associated with higher motivation, optimism and persistence which, in turn, may lead to a greater sense of personal control (Taylor and Brown, 1988; Dodds et al, 1994). Furthermore, having a "wished for" future is one component of hope (Nunn, 1996). The implication here is that interventions which encourage patients to maintain or enhance the motivational structure of their lives, and be future-oriented (i.e. develop plans and goals) are likely to prevent the development of depression and encourage the encapsulation of the disease. Again, this constitutes a strategy to prevent the development of maladaptive assumptions (e.g. "What's the point in planning anything?") by strengthening beliefs in personal efficacy. At the same time, pre-existing assumptions about life goals must gradually accommodate any limitations imposed by the disease.
LOSS OF SOCIAL SUPPORT

The diagnosis of cancer plunges people into a surreal world in which the individual can feel profoundly isolated and alone. Whatever the objective prognosis, it also confronts patients with the prospect of permanent separation from loved ones that will inevitably occur at the moment of their death. The examination of this stark reality is profoundly distressing, not only because of their fear of leaving the world alone, but also because people tend to anticipate the grief reaction of their survivors. Parents, in particular, commonly worry about the fate of their children after their death.

One of the paradoxical responses that people sometimes make as they contemplate future separation from loved ones, is premature withdrawal. Separation anxiety is not, of course, unique to the patient and may be acutely experienced by those most dependent on the person facing the illness; in these circumstances the patient may attempt to protect their dependants by not talking about their predicament, thus reinforcing their isolation. However, sometimes withdrawal is a caring but misguided desire to begin the process of separation early in order to prevent profound loss on the day of death.

Assumptions about relationships involve considerable assimilation and accommodation over the course of a cancer illness as both the patient and his or her significant others adjust to role changes brought on by the illness and its treatment. For example, anger is likely to be directed towards those who have 'disappointed the assumptive world' by not having behaved as the individual might have wished, and this may even lead to enduring but stressful changes in these relationships, and possibly further social isolation.

However, although the social network may be a source of stress, social support is an important resource in coping with cancer (Dunkel-Schetter, 1984; Wortman, 1984; Neuling and Winefield, 1988) and is widely held to be an effective buffer against the effects of stress (Cohen and Wills, 1985). It is positively related to mental health and negatively related to physical illness and
mortality (Janoff-Bulman, 1992). Social support helps in the rebuilding of the shattered assumptive world by providing a safe context in which individuals can reassess the world, their role within it and their self-worth (Janoff-Bulman, 1992; Parkes, 1988). Thus, interventions which enhance the provision of social support are likely to prevent the affective disorders which are so common in cancer.

**Adjustment and Quality of Life**

Kenneth Calman (1984) has defined quality of life as the gap between what people expect and what they actually experience: "Quality of life measures the difference, at a particular period of time, between the hopes and expectations of the individual and the individual's present experience" (p. 125). Poor quality of life may be assumed to involve the loss of something formerly expected from life, even though the individual may have been previously unaware of their expectation. In short, quality of life is wholly subjective, not a score against a normative table of functional ability. It reflects a very personal view of the world, consisting of the individual's perception of current reality which is compared with acquired assumptions that have been shaped by the individual's goals and expectations coupled with (an almost spiritual) sense of justice in the universe.

From a social cognitive view these expectations are psychological constructs which can vary over time according to present and past experiences; they constitute one major domain of the assumptive world. Like the assumptive world, expectations are 'pre-conscious'; that is, available for scrutiny but rarely consciously examined (Janoff-Bulman, 1992). People are often not aware of what constitutes their quality of life and their assumptive world until they are "disappointed" by some important feature of them.

There are two immediate implications of this in terms of defining adjustment to illness as an end-point and as a process. First, adjustment as an end-point may be viewed as a return to pre-morbid levels of quality of life; either the negative
effects of the illness have passed, or assumptions/expectations are recalibrated to accommodate or assimilate the implications of the illness. Second, adjustment as a process may be viewed as any steps that are taken to facilitate this recalibration of assumptions/expectations or the assimilation of the implications of the illness.

For example, a woman who has had a mastectomy has to cope with the incongruence between her assumptions and expectations about her body and the reality of her altered physical appearance, capability and sensation. These negative effects of her illness may be partially reversed through breast reconstruction surgery. On the other hand, her quality of life may return to near premorbid levels as she learns to “adjust” to her altered physical state: her expectations and assumptions about herself (both physically and psychologically) adapt to her new reality (accommodating it) while her appraisal of her body-image and general self-image may improve as she habituates to her body changes (assimilation). A sense of closer congruence between expectations and reality is thus re-established, along with something which may approximate premorbid quality of life.

**Conclusion**

It has been argued that adjustment is not simply the end-point of an individual’s cancer journey but, rather, an active psychosocial process which may include both positive and negative consequences for the individual and which may contain the seeds for the later development of psychological disorders and interpersonal problems. Both the coping and social-cognitive literatures offer a theoretical understanding from which useful hypotheses for the prevention of these problems may be derived.

Hospitals have been viewed as “communities whose purpose is to facilitate the process of psycho-social transition” (Parkes, 1971). In particular, Parkes (1988) has suggested that in facing a transition, such as the experience of cancer, individuals may be helped by trained volunteers. He and others (Brennan and
Sheard, 1994) point out that those who have fully completed a similar transition themselves may be a valuable source of guidance and support to those starting their journey. In view of the high incidence of cancer and concomitant distress, the deployment of trained cancer survivors offers a cost-effective and practical way forward towards helping people adjust to this disease and restore some measure of quality to their lives.

References


Professional Work History

1992 - present  Consultant Clinical Psychologist (B Grade), Bristol Oncology Centre, Bristol

1985 - 1991  Senior, then Principal Clinical Psychologist, Adult Mental Health and HIV/AIDS, Bloomsbury and Islington Health Authority, London

1981 - 1985  Basic Grade, then Senior Clinical Psychologist, Adult Mental Health, Enfield District Health Authority, Middlesex

Clinical Experience

- Individual therapy (cognitive-behaviour therapy, brief psychotherapy, bereavement counselling)
- Couples/marital and family therapy
- Group therapy: long-term analytic group psychotherapy; agoraphobia groups, anxiety-management groups, social skills groups, relaxation groups, cancer-phobia group, tranquilliser withdrawal groups, assertiveness-training groups, psycho-educational courses for people with cancer.
- Short-term interventions in primary care settings
- Clinical Specialist in HIV and AIDS 1986 - 1991
- Clinical Specialist in psychological aspect of cancer (1991 – present)

Staff Support / Supervision / Team Building

Support/supervision

- Psychiatric Day Hospital nursing staff (group)
- District Nurses and Health Visitors seeing clients with AIDS (group)
- Newly-qualified District Nurses and Health Visitors (group)
- Community Psychiatric Nurses (group);
- Accident and Emergency multi-disciplinary team (group)
- Therapeutic radiographers and oncology nurses (group)
- Individual members of multi-disciplinary team
Team building with:

- Community Mental Health Resource teams
- Health Visitors team
- Physiotherapy Department
- Social Services managers of homes for the elderly.

Management Experience

- Chair of Islington District HIV/AIDS Counselling Group (1986-1991)
- Founder member of Islington District AIDS Co-ordinating Group (1986)
- Founder member of Islington District Care of the Dying Group
- Bereavement Support Co-ordinator, Islington Health Authority
- Founder and Co-ordinator of Islington Community AIDS/HIV Resource Centre – iCARE, The Angel, Islington
- Chair of Bristol Oncology Centre Psychosocial Forum
- Manager of Bristol Oncology Centre Cancer Support and Information Centre
- Head of Psychosocial Department, Bristol Oncology Centre
- Founder and Membership Secretary of Special Interest Group of Clinical Psychologists in Oncology
- Executive Member and Newsletter Editor of British Psychosocial Oncology Society (1992-1997)

Teaching / Training

Supervision of clinical psychology trainees from the North East London Polytechnic, University College London, University of Exeter, and University of Plymouth. Research Field Supervisor for Doctoral Clinical Psychology Trainee.

Teaching on clinical psychology training courses on HIV/AIDS, death and bereavement, and psychological aspects of oncology to North East London Polytechnic, University College London, University of Exeter, University of Plymouth, South Wales training scheme, University of Bath (Health Psychology MSc)

Workshops, lectures and tutorials to various groups on:

- counselling the dying and bereaved
- counselling
- relaxation therapy
- cognitive-behaviour therapy
- service development issues in psychosocial oncology
- assertiveness training
- care of the dying
- communication issues in intensive care
- breaking bad news
- team building
- burn-out and stress-management
- psychological aspects of HIV/AIDS
- ENB courses (e.g. Teaching and Assessment in Clinical Practice)
- psychological aspects of chronic illness
- “difficult” patients
- psychological aspects of cancer
- psychological aspects of palliative medicine
Personal Training

- Two-year introductory psychotherapy course for psychologists and psychiatrists (Tavistock Clinic)
- One-year introductory course in Group Analytic Psychotherapy (Institute for Group Analysis)
- Several one-day and two-day courses on cognitive-behavioural psychotherapy
- Two-day Regional training course on HIV/AIDS
- Individual training days on working psychologically with people with HIV and AIDS
- Three-day APT workshop on issues to do with death and dying
- Three-day bereavement counselling workshop
- Three-day course on Adjuvant Psychological Therapy for Cancer Patients (Royal Marsden Hospital)
- Measuring Clinical Effectiveness day seminar
- Avoiding Problems in the Design of Randomised Controlled Trials seminar
- Two-day symposium on Attachment Theory and Couple Relationships (Tavistock Marital Studies Institute)
- Two-day residential seminar on breast cancer
- Two-years of weekly supervision from Institute for Group Analysis
- Therapy supervision for work with individuals, couples and families
- Experience of 2½ years of individual psychodynamic psychotherapy
- Experience of 16 sessions of Cognitive Analytic Therapy (CAT)

Papers / Publications


Brennan, J. (1990) *Coping with Death - The first few hours*, Bloomsbury and Islington Health Authority for bereaved in Islington

Brennan, J. (1990) *Coping with Death - A guide to the days ahead*, Bloomsbury and Islington Health Authority, for bereaved in Islington
Brennan, J. (1991) *Post-Traumatic Stress Disorder and the Gulf War*, report for Islington Health Authority in preparation for Gulf War casualties,

Brennan, J. (1991) *Caring for the Dying and Bereaved in a Multicultural Health Authority*, Bloomsbury and Islington Health Authority


SELECTION, REFLECTION AND CLINICAL PSYCHOLOGY

Abstract

Professional training in clinical psychology is currently one of the most sought-after post-graduate courses in the UK. The aim of clinical training is to provide trainee practitioners with sufficient instruction in the theory and intervention techniques of the discipline to be allowed to practise relatively autonomously at the end of its three years. Yet there still appears to be conceptual confusion as to how much the practice of clinical psychology is an academic science and how much it is an interpersonal encounter.

It will be asserted that the personal qualities and skills of practitioners play an essential role in determining the nature of interactions with clients, not simply the techniques which they may be able to offer, or their academic knowledge or rigour. It will be argued that clinical understanding is based not only upon theoretical and empirical knowledge, but also upon the psychologist's constructions of their client's behaviour and that these constructions are shaped by the psychologist's own assumptive world and personal qualities. Increased self-awareness is often one of the tangible benefits of psychological intervention for many clients but it is unclear how much ongoing self-awareness or reflexivity is expected of the clinical psychologist in their professional role.

It will be argued, on the basis of preliminary survey data, that with the growing emphasis on academic achievement in the selection of candidates for clinical training programmes, some of the most important variables in whether or not a person develops into an effective and safe practitioner (e.g. empathy, the capacity for reflection etc.) are not being consistently assessed. This paper will ask whether the profession should be selecting trainees on the basis of personal qualities, and whether, in fact, training courses are doing so.
Finally, as an exercise in personal/professional reflection itself, this paper points to the need for training courses, and the profession as a whole, to reflect carefully on the interface between personal and professional life throughout the career of the practitioner.
"Which other profession is better placed to have insights into the phenomenology, wishes, uncertainties and irrational discrepancies in the mind of the client? Which other profession is better placed to reflect on itself, on its own defence mechanisms, its false attributions, and its fear and on the coping strategies available to increase its effectiveness?" (Gale, 1997, p.13)

"The core implementation skills arise from the use of psychological knowledge and include: problems-solving skills, inter-personal skills, listening skills, communication skills... interpretative skills, consultative skills, and skills needed to apply psychological therapeutic theories.” (Manpower Advisory Service Report on Clinical Psychology, 1989, p. 44)

"A common attribute of experienced clinical psychologists is that they have built their own ‘model’ – usually an amalgam of other theoretical perspectives – which informs their own work.” (Manpower Advisory Service Report on Clinical Psychology, 1989, p. 41)

**Introduction**

The experience of preparing this thesis, of being a student again, has provided a welcome opportunity to reflect on my development as a clinical psychologist in light of the training I received, and to ask questions about the relationship between training and some of the core issues in my clinical practice. It will be my contention that personal and professional reflexivity are essential to professional development but that this aspect of clinical psychology has been historically neglected due to its scientifically challenging nature. The writing of this paper has therefore been an iterative reflective process in itself, though this
quite personal dimension is difficult to convey without it appearing arrogant or self-indulgent. The paper makes no claims on originality or "truth" per se but, like clinical work itself, presents a combination of evidence, conceptual models and personal reflection. It is thus, in some ways, an embodiment of the subject under discussion.

After reflecting on the nature of psychological knowledge, and the role of the construction of meaning in clinical work with adult clients, the paper will present pilot survey data on the particular issue of 'gate-keeping' within the profession. These will include the perceptions of both trainees and trainers as to what are the important criteria for selecting prospective candidates for training in clinical psychology. These data assume no pretensions regarding their scientific rigour or objectivity. In fact, like clinical work itself, the "case-study" of this paper, the problems to be discussed are variably defined and difficult to operationalise. The conclusions drawn are, undoubtedly, a matter of "clinical opinion."

Psychological Knowledge and the Construction of Meaning

"There is no doubt that theory has a place in psychotherapy. We do need a framework with which to think, but it may be that the relationship with the other should take priority" (Crellin, 1997)

Helping to reduce distress through personal self-awareness is obviously a central tenet of a great deal of clinical or applied psychology with adult patients. The British Psychological Society's (BPS) Division of Clinical Psychology (DCP) has stated that the "central focus" of clinical psychology is "the value it places on the experience of individuals and their attempts to understand that experience" (BPS, Undated, p2.). However, it has been argued that, from its origins at the Maudsley Hospital, UK clinical psychology has "sought legitimacy via British 'aggressive scientism' rather than through the practices rooted in the continental traditions of phenomenology" (Pilgrim and Barnes, 1989). This suggests that clinical psychology in Britain may contain conceptual and philosophical contradictions at its core; to what extent can clinical practice be scientific and objective and how much is it necessarily (inter)personal and subjective?
Scientific experiment can undoubtedly lead to more refined models of the world and is a necessary and vital component for the development of many aspects of knowledge, including that of human self-awareness. As is well known, George Kelly (1955) took this view of human conceptual development. However, although its polar opposite may be blind faith, science is not the only medium for the acquisition of psychological knowledge. Furthermore, the practice of clinical psychology requires more than the application of factual knowledge (Mollon, 1989); it requires the capacity to blend a number of interpersonal and listening skills with a knowledge of theoretical models of human behaviour, in order to help the client achieve a new level of self-awareness (which may, in turn, lead to behaviour change). In other words, clinical psychology is not simply the practice of good science or academic ability; it is also the application of some essential personal skills, some of which will be explored below.

Clinical psychology purportedly offers more depth of understanding than non-interpretive therapeutic approaches (e.g. client-centred therapy) and therefore, as such, is more subject to “top-down” or conceptually-driven processes (Norman, 1976). In other words, psychologists are able to apply quite sophisticated models of behaviour to the raw information conveyed to them by their clients. Models, however, simply provide a structure (or construction) through which behaviour may be better understood; they do not provide ‘truth’ or ‘meaning’. Modern social constructivists point to this distinction between observation and meaning:

"It is the context that interacts with the objects of observation to produce the elements we endow with meaning. Nothing means anything on its own. Meaning comes not from seeing or even observation alone, for there is no ‘alone’ of this sort. Neither is meaning lying around in nature waiting to be scooped up by the senses; rather it is constructed. Constructed in this context, means produced in acts of interpretation."

(Steedman, 1991)
Kelly’s adoption of the philosophical notion of constructive alternativism, speaks to this same idea:

“There are always some alternative constructions available to choose among in dealing with the world...no one needs to be the victim of his biography.” (Kelly, 1955, p.15)

Unlike the medical model with its emphasis on achieving a diagnosis, clinical psychologists (of any theoretical persuasion) attempt to contextualise ‘problems’ by placing them within a matrix of influencing variables (whether historical or current). This capacity to collate and accurately synthesise the many, often ‘woolly’ variables that influence a client’s presenting problem into a plausible ‘current working hypothesis’ (i.e. construction or formulation) may be enhanced by training (which provides theoretical models) and clinical experience, but ‘experience’ is a commodity which is not confined to what has been learned in the consulting room. Psychologists bring their own personal sensitivities, strengths and fears to their encounters with clients.

Paradoxically though, without some personal involvement in our clients’ stories, we are unlikely to get anywhere near the truth of their experiences. The objective facts of the story alone are rarely sufficient; we are forced to immerse ourselves temporarily in that experience in order to make sense of it. Thus, if “perceiving is a constructive process”, a fact which has been widely accepted by cognitive psychologists for three decades (Neisser, 1967, p.95), then the work of psychologists cannot simply involve the objective application of discrete theories and therapeutic techniques. Their understanding and behaviour are a function of the constructions that they uniquely and subjectively place on what is observed. In short, as the Manpower Advisory Service (MAS) report accurately stated, clinical psychologists build, and are informed by, “their own” models (Manpower Advisory Service Report on Clinical Psychology, 1989 Report, 1989).
What personal qualities are needed among clinical psychologists?

To summarise, clinical psychologists have theoretical models to help them contextualise and intervene in human problems: models of development and learning, models of appropriate therapist behaviour, and models of therapeutic intervention. These various models (some of which have been empirically validated) help psychologists shape a working hypothesis of their client’s presenting problem so that they can begin to understand how it developed and how it is maintained. But, as has been argued, clinical psychology also involves sophisticated inter- and intra-personal skills which reside differentially within people and which are commonly acknowledged as helpful in the therapeutic process. A few of these will now be examined.

EMPATHY

Empathy is a highly valued hallmark of data-driven, therapeutic models such as client-centred therapy. It is perhaps less highly valued by the more theory-driven therapies, such as behavioural and cognitive-behavioural therapy, which are so widely taught in clinical psychology training courses. This is ironic in view of its potentially more important role in these more ‘interventionist’ models. Interestingly, highly top-down interpretive therapies, such as psychodynamic psychotherapy for example, do appear to place greater emphasis on the value of empathy.

The capacity to empathise with another person is presumably derived from a person’s personal history and psychological development (it appears to have close parallels, for example, with the child’s development of a theory of mind, a concept which has been termed “reflective function” [Fonagy and Target, 1997]). It is interesting to note in this context that the word “sensitivity” has two meanings: (1) easily affected emotionally by events and other people, and (2) acutely perceptive and aware of others’ emotions. The former suggests a tone of personal vulnerability while the latter suggests someone empathic. It
may be no accident that the word has two meanings for it seems likely that a person's capacity for empathy is largely drawn from their own personal vulnerability. (If so, this also raises the interesting question as to whether psychological practitioners do their best work in areas where they feel most vulnerable or whether these therapeutic fields are chosen by practitioners in order to confront their fears.)

INTUITION
Claxton (1998) has recently reviewed the concept of intuition and recent scientific work which is beginning to shed light on this neglected and unpopular notion. It appears that intuition is non-conscious, non-intellectual learning and that it is superior to conscious intellectual learning in tasks which involve, over time, complex patterns of contingency (e.g. several variables simultaneously and/or sequentially influencing one another). Claxton indicates that such implicit learning or intuition "requires tolerance of a temporary state of confusion, and that complex, counter-intuitive predicaments are better mastered if this state of confusion – having given up the attempt to generate and hang on to conscious hypotheses – has been induced" (p.218). Indeed, intuition may rely on information which is both inarticulate and of a faint or fleeting quality.

These findings may have a significant bearing on the capacity of psychological therapists to mesh the many variables being described by the client into a perceptive and meaningful whole (i.e. a formulation). Far from relying only on an intellectual or academic understanding of the client's problems, this suggests that therapists would do well to learn to 'tune in' to non-conscious, non-intellectual, empathically-derived information in order to arrive at insights, interpretations and formulations. It is interesting that Claxton's description of a state of non-intellectual receptiveness corresponds very closely with what Freud called the importance of the analyst's "free-floating" attention, and what later psychoanalysts referred to as a receptiveness to information derived from thoughts and feelings generated in the counter-transference (Sandler, Dare and Holder, 1973).
Certainly, my own clinical work has given me examples of reaching an insight about the client, what the Gestalt Therapists have aptly called an “Ah-ha!” experience, only to have to spend the next minute working out in my (intellectual) mind how I arrived at this sudden thought (a mental equivalent to ‘reverse engineering’). Although perhaps scientifically unreliable due to their post-hoc retrospective nature, the validity of these moments of “inner sight” or insight are often confirmed by the fact that the client has reacted with a strong identification with my subsequent interpretation or observation.

REFLEXIVITY (AND CLINICAL SUPERVISION)
Clearly, all the aforementioned clinical components – sensitive empathic insight, intellectual and emotional reflection and self-awareness by the therapist, and the capacity for effective synthesis and integration – are all essential for the progress of good therapy. In addition, the most essential skill of any therapist is their capacity to draw upon these components in order to make a therapeutic ‘response’ of some sort (to enable the client’s therapy to progress.) This response can be anything from a nod of encouragement, to a key therapeutic interpretation. The basis of this crucial skill is probably largely taught in the context of trainee placements and the medium for its teaching is generally clinical supervision.

In effective clinical supervision, the trainee is encouraged to reflect on their own behaviour, that of their client, and the various sources of information for the responses that they may or could have made. In other words, supervision helps to contextualise the trainee’s own behaviour by providing “alternative constructions” in order to derive further understanding and self-awareness, in much the same way as psychologists work with clients. In this way, the trainee’s reflexivity is encouraged and their clinical skills are refined.

It could be argued that this capacity for reflection and subsequent adaptive recalibration defines all successful systems and organisms, including those of
relationships and individuals; without it, learning and skill development are impossible. Psychologists work within a personal, social and ethical context and all have a bearing on the psychologist's constructions. Reflexivity enables some of these pre-conscious influences to become conscious. Scientific method is one form of such reflexivity but there are a number of other ways in which such reflexivity can be mediated. For example, writing can be a self-reflective process and can lead to a clearer understanding of what it is one feels and believes; e.g. writing an accurate clinical formulation involves both a measure of reflection and discovery. Clinical supervision, however, is a more deliberate and focused method of encouraging clinicians to consider the perceptions and constructions that they bring to their work. In short, the capacity to be self-critical and reflective is a personal quality which is essential to personal and professional development. The provision of adequate supervision opportunities, on the other hand, is essential to the maintenance of standards within the profession.

Gate-keeping the profession

If one accepts the premise that clinical effectiveness is, at least in part, a function of the practitioner's personal qualities, the corollary must be that some individuals are more suited to the work of therapeutic clinical psychology than others. Few psychologists would be arrogant enough to deny the existence of individuals who have no formal training in either psychological therapies or science but who, nonetheless, possess a "natural gift" for psychologically helping others.

This leads to the idea that the profession should be 'gate-keeping' itself by selecting and vetting candidates, at least in part, on the basis of their personal qualities, even if the culture of clinical psychology is the very antithesis of being judgmental about people. (Clinical placements, for example, are never likely to be an effective method for "weeding out" unsuitable trainees; ironically, it may be the very fact that most clinical psychologists aspire to be fair-minded, flexible and, above all, non-judgemental that gate-keeping the profession is such a problematic area).
Assuming that such desirable and undesirable qualities do exist, it would be ironic if the profession of clinical psychology, with its origins in psychological testing, has yet to reach an explicit consensus on what these qualities are or, indeed, what methods would enable them to be assessed. To what extent then do training courses vet and select candidates in terms of personal qualities? In order to begin to answer this question I conducted two small, informal pilot surveys. These surveys do not pretend to be scientifically rigorous but are merely exploratory and descriptive in nature.

**Trainee Survey**

**METHOD**

First I asked twenty clinical psychology trainees (all in their third years but from three different training courses) to complete a short informal survey questionnaire (Appendix 1), of unknown reliability but reasonable face validity, concerning the selection procedure which they had undergone. Twenty subjects were clearly not necessarily representative of the annual intake of three hundred clinical trainee across the UK at that time (Gardner, 1997); they were trainees I met in the context of teaching (they were otherwise unselected), but all were asked to return their questionnaires anonymously by post and all did so.

**RESULTS**

The following summary of this small survey indicates little emphasis on personal qualities in the selection process. (The numbers in brackets refer to the number of respondents answering thus)

1. What questions were you asked at the Personal Interview when you applied to the course?
   - *How do you handle stress? (14; 70%)
   - *Why do you want to be a clinical psychologist? (9; 45%)
   - *What do you like to do in your spare time/hobbies? (5; 25%)
   - *There was no personal interview (4; 20%)
What makes you laugh (4; 20%), upset (1; 5%), angry (2; 10%)?
What are your strengths and weaknesses? (2; 10%)
What has been the most traumatic issue you have experienced in your work so far? (1; 5%)
My impression was that the panel was assessing whether they would want to share a cup of tea with me (1; 5%)

2. Do you feel that this process accurately assessed your suitability for being a clinical psychologist?
   Yes (3; 15%)
   Yes but you can fake it (1; 5%)
   No (10; 50%)
   (e.g. "I had rehearsed some answers and others were what I thought they wanted to hear; very light-hearted but not very searching")
   Yes and No (6; 30%)
   (e.g. "The questions were so predictable; Motivation yes, suitability no; People need to be asked what they get out of being a therapist")

3. When you applied for the course do you believe that you were aware of your personal motivations for becoming a clinical psychologist?
   Yes (14; 70%)
   No (6; 30%)

4. Do you feel that the past three years have made you clearer about your motivations for becoming a clinical psychologist?
   Yes (17; 85%)
   No (3; 15%)

5. If so, what have been the main factors which have helped clarify these issues? (9 people responded to this item)
   Supervision (4; 44%)
   Personal reflection (4; 44%)
   Discussion with peers (2; 22%)
   Personal therapy (3; 33%)
   Exposure to different settings and approaches (1; 11%)

6. What do you feel are some of the factors that would make some people unsuitable to become clinical psychologists? (10 people responded to this item)
Lack of self-awareness/insight about how our own vulnerabilities or unresolved personal issues impact on clinical work, or how clinical work impacts on us (8)

Poor social/communication skills (4)

Rigidity of approach/Lack of ability to take account of several perspectives (3)

Lack of empathy/ability to listen (3)

Psychotic or personality disorders (2)

Limited life experiences (1); Lack of: sense of humour (1), creativity and imagination (1), academic ability (1), assertiveness (1)

7. How important do you feel being in some form of personal therapy is as part of clinical psychology training?
   - Extremely important (6; 30%)
   - Fairly important (4; 20%)
   - It depends on the individual (8; 40%)
   - No answer (2; 10%)

8. Are there any other comments you would like to make about “gatekeeping” in clinical psychology?
   - Too much emphasis on the scientist-practitioner model. This has led to the over-focusing during selection procedures on academic performance aspects of individuals profiles.
   - The system is too tunnel-visioned for getting onto courses. Is there a way of encouraging a more open-minded approach in trainees, to avoid clinical psychology evangelism which seems to be perpetuated by the current system? Perhaps we need to open the gates more.
   - With the introduction of doctorates, it feels as if courses are beginning to focus more on academic credentials. Perhaps a more formal structure for assistant psychologists, both with regard to career progress and assessment of ability, would be more relevant in assessing individuals suitability.
   - Academic skills are very important, but they may carry too much weight at interviews. Academics on clinical courses are not typical clinicians. If anything, they are a bit short on social skills themselves.
   - I think it would be helpful if people had personal therapy before training but I certainly think it should be part of training for anyone wanting to be a therapist in terms of understanding
yourself but also in being able to empathise more fully with how clients feel in coming to see a psychologist.

- It would be better to have a more apprentice style training entered at a Assistant level and moving through specialties, with a BPS input, away from universities. Interpersonal problems between existing trainees and course teams shapes the recruitment of following cohorts. In this way a dialectic swing occurs from one cohort to the next (i.e. existing cohorts are the antithesis of past cohorts).
- Either enhance the status of Assistant Psychologists (e.g. work counts towards qualification) or scrap the role. Beware of training courses becoming too academic-centred.
- The process of assessment of personal suitability to practice should be ongoing, i.e. there should be some form of monitoring of mental state and current life problems. Everyone has times of crisis and this should be addressed through an ongoing mentoring or supervision system.

**SUMMARY**

This small survey produced surprisingly consistent responses in view of fact that the trainees were drawn from three different courses. Apart from asking how trainees cope with stress and why they wanted to be a psychologist, there was little consistency in the “personal questions” they were asked, and little sophistication in the questions themselves. Half the sample did not feel that the selection process adequately assessed their suitability to become clinical psychologists.

It is reassuring that 17 of the 20 respondents felt that their motivations for working in the field had become clearer to them and four of the nine people who commented on this cited supervision as having helped. There was a strong theme of personal reflection with respect to what had been helpful in clarifying motivations for becoming a psychologist (question 5) though this “monitoring of process”, as one respondent referred to it, appeared to be largely secondary to clinical experience and supervision or, indeed, personal therapy, rather than being one of the key foci of the course. Three of the nine people who responded to this item had found personal therapy to be helpful in clarifying their motivations, while exactly half of the respondents viewed being in therapy as either extremely or fairly important as part of clinical training.
Trainees appeared to have quite clear and consistent views about the qualities that would be unsuitable in clinical psychologists, and a number of them expressed concern that clinical courses over-emphasise academic skills.

It could be argued that the trainees' awareness of these issues is ample demonstration that the selection process had worked in their case. But equally, it could be argued that, rather than being enhanced by the courses, the clinical and personal reflexivity of the trainees has been maintained despite the more academic emphasis of the courses.

Course Directors Survey

METHOD

In order to find out how courses are addressing the problems of selection, I sent another confidential questionnaire (Appendix 2) to all 24 UK clinical psychology training courses, of which nine (37%) responded. In view of this low response rate, the results should be viewed with caution since they may not be representative, nor reflect best practice, and are, in any event, rooted in the time in which the survey was conducted (early 1998). The questionnaires and cover letters were addressed to course directors though there is no guarantee that it was they who completed them. Two of the respondents took issue with structure or 'purity' of the questions themselves rather than attempting to answer them, while all the others appeared to have no difficulty understanding what was intended by the questions.

SUMMARY OF RESULTS FROM COURSE DIRECTORS' SURVEY

Because it is difficult to summarise objectively the results from the course directors' survey, their largely verbatim responses can be seen in Appendix 3 (page 96).
The academic bias referred to by the trainees was evident though not as pronounced as might have been expected. The selection process appeared to favour academic achievement (weighted across the courses as 34%) over past experiences (19%) and performance at interview (17%), but there was considerable variability in the importance placed on personal qualities as opposed to academic abilities. In fact, one or two respondents appeared to have a rather limited understanding of what was meant by 'personal qualities' when they were asked (in question 4) what personal qualities they sought in a candidate (e.g. “practical... interest in current affairs”, “motivation to succeed, interest in people, organisation of work”).

Personal qualities were assessed primarily in the context of selection interviews though only two of the courses conducted specifically personal interviews; most assessed personal qualities as one dimension of the clinical interview. It was interesting to note that one course had conducted research into their selection procedure and found that openness was “the key personal quality” they were selecting for, though it would have been useful to have had an operational definition of this term. Only this course and three others referred to the importance of reflexivity or self-awareness, and only two courses mentioned empathy. Other sought-after qualities tended to emphasise motivation, social and interpersonal skills (such as warmth which may be similar to openness), and the ability to cope with stress.

Of those who made explicit the personal criteria they were selecting for, one course sent a copy of the personal interview panel rating form. This included numbered scales from 1 (Unsatisfactory) to 7 (Excellent) relating to four items: interpersonal skills, ability for listening/sensitivity and self-reflection, affect/warmth and openness, and personal insight/ability to cope. This is clearly a more sophisticated approach to selection than having no explicit criteria at all as was the case among three of the nine courses.
Negative qualities tended to be similar to those suggested by trainees: personality disorders or deficits (e.g. self-centredness), poor interpersonal skills and relationships, insensitivity and lack of self-awareness. However, only four of the nine courses made these potential criteria for rejection explicit among the selection panel.

All respondents believe that their interview process to be moderately valid, reliable or fair, though again there was some variability. Interestingly, 7 of the 9 respondents believed that at least one trainee in the past five years had been unsuitable to become clinical psychologists for reasons of personal qualities, constituting 12 trainees in total. However, it is unclear how many of these people became qualified and if one assumes, very conservatively, that courses trained over five years the maximum number within the range marked on question 1, this would correspond to only 1.6% of all trainees being later deemed unsuitable. Indeed, responses to the last question suggest that most courses are content with their selection system and do their best within the limited resources at their disposal.

Other approaches to selection

I also contacted both the American Psychological Association (APA) and twelve doctoral clinical psychology training courses in the United States, of which three responded. The APA sent me a copy of the Guidelines and Principles for Accreditation of Programs in Professional Psychology, with a note explaining that selection is left up to the graduate programmes. While specifying that each training course must “adhere to and make available to all interested parties formal written policies and procedures that govern intern selection...” (p. 11), the 37 page document makes no reference to what personal qualities courses might wish to seek or avoid in prospective interns.

One respondent from a US graduate school stated that his course uses the interview to “deselect people who clearly have inappropriate personalities”
though admitted that they do not use explicit criteria for doing this: "True comment made at an interview: 'my doctor thinks I should be able to go off antidepressants in the very near future.'" The same respondent said that the University of Minnesota use their Minnesota Multiphasic Personality Inventory (MMPI) and that a few other US universities also use psychometric tests. As for himself, he said he would favour using a personality test to measure the candidate's "social orientation and views of themselves", though he said that a better, albeit expensive, way would be to have the applicant interview a disturbed person and "find out what their level of comfort and empathy is."

A second respondent noted that their selection process aims to find a match between the aspirations of the candidates and those of the programme though added "We do, on occasion, notice behaviors or attitudes expressed during the applicant's interviews which seem incompatible with professional clinical work."

The last US respondent sent a copy of the form sent to referees by their university. This constitutes a list of eleven qualities which the referee is required to rate according to a scale ranging from "very low" to "truly outstanding". The eleven qualities are: academic ability; creative, innovate thinking; capacity for objective evaluation of self (sic); energy level at work; empathic capacity; maturity of judgement; conscientiousness; ability to work closely with others; ability to work independently; capacity to handle stress; open-mindedness, tolerance for deviance. Among other questions, are a further ten which require the referee to rate the candidate according to "personality characteristics which would interfere with his/her functioning in the clinical role". These include: anxious, fearful; dependent; low self-esteem, unusual need for approval; hostile, angry; pushy, aggressive; manipulative etc.

Unfortunately, the form makes it clear that federal law permits the candidate access to the document, thus probably diluting its ultimate validity. However, compared with the confidential guidelines for referees issued by the UK Clearing House for Postgraduate Courses in Clinical Psychology, the form is impressively
detailed. The UK guidelines simply ask the referee to comment on the candidate’s “overall suitability for training as a clinical psychologist, interaction with others..., and identification of strengths, needs and weaknesses.”

The United Kingdom Council for Psychotherapy (UKCP) (personal communication) also assesses psychotherapy trainees through interview, but then insists that successful candidates be in personal therapy themselves throughout the duration of their training. There is not, as yet, a UKCP policy on how the requirement of personal therapy is assessed but the issue of personal suitability is largely conducted through the trainee’s Personal Development Profile and Personal Learning Journal. The former is based on information written in the latter, as well as self-assessment and peer-assessment. It aims, among other things, to assess the student’s ability to reflect on the relationship between personal development and professional practice, and requires a “commitment to personal growth and development.” The clinical supervisor is also required to indicate whether the student “shows some ability to integrate personal awareness, knowledge and skill with clinical practice.”

Within psychoanalysis, a training analyst is expected to pronounce on the success of the trainee/analysand’s therapy before the latter is permitted to proceed to becoming an analyst themselves. While some have viewed this as a rather radical, even paranoid, form of gate-keeping with inherent contradictions (Young, 1996), it nonetheless represents one end of a continuum, with the other end being no attempt to examine who passes through the door into the profession.

Regardless of how one views the methods of gate-keeping within psychoanalysis and psychotherapy, these disciplines believe that it is essential to examine the motivations and conflicts of their practitioners. The choices people make, including their choice of profession, can and should be subject to scrutiny in order to protect the public from practitioners who may harbour dubious ethics, potentially damaging personal motivations of which they may be only partially
aware, or even inappropriate interpersonal behaviour. Although such scrutiny currently appears to be inconsistent at the point of entry into clinical psychology, some courses do encourage trainees to maintain "reflective journals" which at least go some way to acknowledging the potential impact that training may have on the individual.

**Conclusions**

There appears to be tacit agreement among trainees, UK and US clinical psychology training courses, as well as UK psychotherapy courses, that the personal qualities of practitioners are an important source of variance in their effectiveness as practitioners. However, in this small survey of UK clinical psychology training courses, even where these issues were addressed, personal and interpersonal qualities were rarely made explicit in the selection procedure, there was little overall consistency among training courses in the way that they selected and vetted prospective trainees for these qualities, and there was not even much clarity about quite what these qualities are. Furthermore, it would appear, on the evidence from both surveys, that the clinical psychologist's personal skills, as well as their growth and development, were tending to be overshadowed by academic requirements. Again, it must be conceded that the evidence presented is of an exploratory, descriptive nature, since the questionnaires were not scientifically constructed and are of unknown reliability and validity. Thus, the questionnaires may have biased the results.

In its pursuance of scientific and academic rigour, clinical psychology may be in danger of failing to nourish the equally valuable contributions of empathy, sensitivity, reflexivity, intuition and insight, qualities which presumably reside differentially within individuals yet are scientifically challenging to operationalise and measure. This is not to say that these qualities cannot be enhanced where they are poorly developed. Trainees find reflective clinical supervision and personal therapy helpful in this regard, but the former is often dependent on the willingness and competence of clinical supervisors while the latter is rarely encouraged and never required.
If, as the quotation from the MAS report at the beginning of this paper suggests, experienced clinical psychologists develop interpretative skills based upon their own particular 'models', this indicates a need for practitioners continually to articulate and reflect on these internal models and assumptions. This sort of reflexivity or personal self-awareness is the very thing that practitioners are able to offer the public, yet only relatively recently has there been an insistence on clinical supervision within the profession (Green, 1995). Rather than viewing the issues as mutually exclusive, Professional Practice Guidelines for clinical psychologists recognise that "personal and professional development often go hand in hand, the one facilitating the other or restricting it" (BPS-DCP, 1995, p.38).

The advent of clinical governance within the NHS provides an opportunity for the profession to acknowledge the awesome degree of trust that clinical psychologists, and others working in any field of behaviour change, are given by the public at large. It is time that the profession reached a consensus on whether or not clinical psychologists' personal skills and qualities should, or even could be the target of vetting and monitoring. Such an approach would not be without dangers or practical difficulties. Charges of protectionism and elitism would be voiced by those fearful that tighter gate-keeping would lead to unwelcome homogeneity, and selection procedures would have to be devised that would demonstrably uphold the principles of equal opportunity. Indeed, such a review might even conclude that there is little special about clinical psychologists and that all desirable therapeutic skills can ultimately be taught. However, no matter the outcome, by reflecting on whether or not we would wish to select trainees on the basis of personal qualities as well as academic ones, we might, in the process, learn something about our beliefs and assumptions.

In concluding this critique of some of clinical psychology's apparent contradictions, it is readily conceded that this particular construction of these
issues is only one of many. It may even be some distance from the "truth" within current clinical psychology selection and training, as construed by others. The writing of it, however, has provided the author with an opportunity to reflect on some of the assumptions and beliefs that influence his own constructions and, in doing so, to clarify some of them. It has been argued that such attempts at reflection, preferably in the context of a dialogue with a clinical supervisor, provide the fuel for both personal and professional development and should be enhanced within the profession of clinical psychology.

References


BPS-DCP (Undated) Core Purpose and Philosophy of the Profession. Leicester: British Psychological Society Division of Clinical Psychology


Appendix 1: Trainee Survey

BECOMING A CLINICAL PSYCHOLOGIST

What questions were asked at the Personal Interview when you applied to the course? (List any you remember)

Do you feel that this process accurately assessed your motivation and suitability for being a clinical psychologist?

YES ☐

NO ☐

Comments

When you applied for the course, do you feel that you were aware of your personal motivations for becoming a clinical psychologist?

YES ☐

NO ☐

Do you feel that the past three years have made you clearer about your motivations for becoming a clinical psychologist?

YES ☐

NO ☐

If so, what have been the main factors which have helped clarify these issues?

What do you feel are some of the factors that would make some people unsuitable to become clinical psychologists?
Appendix 1: Trainee Survey (2)

What would be a fair and practical way to assess these factors?

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

How important do you feel being in some form of personal therapy is as part of clinical psychology training?

- Extremely important □
- Fairly important □
- No opinion □
- Fairly unimportant □
- Totally unimportant □

Any other comments you would like to make about "gate-keeping" and clinical psychology?

____________________________________________________________________________________________

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Thanks for your help!
Appendix 2: Clinical Psychology Trainee Selection Questionnaire

This questionnaire is anonymous; results will be grouped and any identifying information about particular courses will be removed. Honesty, however, is essential if this exercise is to have any value.

1. On average, how many trainees does your course take per year?
   - <5 □
   - 5-10 □
   - 10-15 □
   - >15 □
   (Do not include top-up/conversion course candidates)

2. What weight (please use percentages) would you give to the following components in selecting a new trainee?
   - Academic achievements
   - Performance at interview
   - Quality of application form
   - References
   - Past experiences (e.g. assistant psychology jobs)
   - Career interests

   (Please ensure that your weightings add up to 100%)

3. In selecting a clinical psychological trainee, what relative weight would you give to academic achievement and personal qualities? Mark the line with an X. (The mid-point which is marked represents equal weight to both dimensions)

   Academic Achievement | Personal qualities

4. What personal qualities in a candidate are you looking for?

   

5. Are these personal qualities made explicit (e.g. written down) among the admissions panel? YES □ NO □

6. What personal qualities in a candidate do you regard as unsuitable in someone who is a potential clinical psychologist?

   

7. Are these personal qualities made explicit (e.g. written down) among the admissions panel? YES □ NO □
Appendix 2: Course Directors' Survey (2)

8. **Personal suitability**
What methods (e.g. application form, references, interview, practical exercises, etc.) do you use to select candidates on the basis of their personal qualities?
*(Please try to rank each component in order of its importance; 1 = most important)*

9. **The Interview**
How many people interview each candidate?

10. On average, how long is the interview?

11. What are you trying to find out from the interview?

12. Do interviewers use explicit (written) criteria to assess candidates in the interview?  
*(If YES, please attach a copy if available, first removing any obvious identifying marks)*

13. Please rate, with regard to personal qualities, the extent to which you believe your interview to be *(0 = Not at all; 10 = Completely)*

   - a valid procedure (it accurately assesses what it purports to assess)?
   - a reliable procedure (it consistently assesses what it purports to assess)?
   - a fair procedure (it is equally valid for all candidates)?

14. In the past five years, how many trainees have you accepted onto your course who you later believed to be unsuitable to become clinical psychologists, for reasons of personal qualities?

15. If you had a free hand to set up a new selection procedure, what would it involve?

---

Thank you very much for your help with this. Please enclose any written criteria used in interviews. Any additional thoughts, comments, documentation and information would be most welcome.

Please return to: James Brennan, Bristol Oncology Centre, Horfield Road, Bristol BS2 8ED
Appendix 3: Course Directors’ Responses

The following is a summary of the results from the Course Directors’ Survey. (The number in brackets following the question refers to the number of responses to it).

**Question 2:** What weights (percentages) would you give to the following components in selecting a new trainee? (6)

<table>
<thead>
<tr>
<th>Component</th>
<th>Mean %</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic achievement</td>
<td>34.44</td>
<td>16.661 - 50</td>
</tr>
<tr>
<td>Performance at interview</td>
<td>16.94</td>
<td>10 - 20</td>
</tr>
<tr>
<td>Quality of application form</td>
<td>11.94</td>
<td>5 - 20</td>
</tr>
<tr>
<td>References</td>
<td>7.77</td>
<td>5 - 16.66</td>
</tr>
<tr>
<td>Past experiences (i.e. jobs)</td>
<td>19.44</td>
<td>10 - 30</td>
</tr>
<tr>
<td>Career interests</td>
<td>10.55</td>
<td>0 - 16.66</td>
</tr>
</tbody>
</table>

**Question 3:** What relative weight would you give to academic achievement and personal qualities (e.g. interpersonal skills and behaviour)? (6)

Respondents were asked to mark a visual analogue scale. Taking the mid-point between academic and personal qualities as zero with a range of 5 in either direction, the mean response was 0.6 in favour of academic achievement though three of the six courses who responded placed more emphasis on personal qualities than on academic achievements. The actual marks have been re-plotted onto the following line:

```
                  Academic    Personal
                          5           5
                          X           X
                          0
                          X           X
```

**Question 4:** What personal qualities in a candidate are you looking for? (9) (Responses are presented verbatim.)

- Enthusiasm; warmth; likeability; ability to use conceptual and social language
- Openness (last year research was done on our selection procedure which included standardised personality measures. Openness was

1 One respondent chose to apportion equal weight to each of the six categories; i.e. 16.66%
confirmed as the key personal quality.) Self-awareness, ability to reflect on strengths and weaknesses, ability to cooperate/negotiate, ability to take initiative, non-verbal social skills, motivation for a career in clinical psychology.

- Good interpersonal skills, an awareness of how to apply psychological principles when discussing a case, ability to describe research work
- Reflexivity about self and others, ability, history of good constructive working relationships, resilience and good coping skills/strategies
- We have developed a person specification which is available if required: warmth, good listening skills, empathy, good time management skills
- First, academic achievement. However, in terms of personal qualities, practical, awareness of limitations, realistic about professional role, interest in current affairs.
- Sensitivity and empathy, good interpersonal skills, ability to get on well with clients and colleagues, reflexiveness/self awareness, open-minded but critical, resilience, ability to cope and prioritise demands of job, maturity
- Motivation to succeed, interest in people, organisation of work
- Motivation for clinical training, ability to handle stress, ability to establish relationships, broad-minded, tolerance, breadth of interest, realistic expectations, empathy without over involvement, warmth.

**Question 5:** Are these personal qualities made explicit (e.g. written down) among the admissions panel? (9)

Yes – 5
Yes, generally – 1
No – 3

**Question 6:** What personal qualities in a candidate would you regard as unsuitable in someone who is a potential clinical psychologist, and grounds for ‘rejection’? (8)

- Arrogance, self-centredness, inarticulateness
- Lack of openness, self awareness; inability to reflect on strengths and weaknesses, inability to co-operate/negotiate, inability to take the initiative, poor non-verbal social skills, poor motivation for a career in clinical psychology
- Someone with obvious personality problems, occasionally noted in references, but generally not. Someone who might not be able to manage the demands of clinical training
- History of destructive interpersonal relationships which could be for a variety of ‘personal quality’ reasons
Lack of awareness of limitations, over-confidence, under-confidence. Unable to think clearly about potential difficulties. Attracted to profession through personal difficulties.

Non-self-reflective, close minded, wedded to a single approach/model, poor interpersonal skills, lacks personal warmth/empathy, evidence of (illegible)

Ego-centricity, manipulation of people, absence of: motivation to succeed, interest in people, organisation of work

Psychopathy, insensitivity, narrow-mindedness, unsuitable for working with others in an organisation

**Question 7:** Are these personal qualities made explicit (e.g. written down) among the admissions panel? (9)

Yes – 4  
No – 4  
No, we tend to focus on positives, rather than negatives – 1

**Question 8:** What methods do you use to select candidates on the basis of their personal qualities?

Most courses specified the interview as the primary assessment method. Two of the courses reported having personal interviews in addition to clinical and academic ones. Others specified the clinical interview as the forum in which personal qualities are assessed. One innovatively ranked a group task as the most important method of assessing the personal qualities of candidates though unfortunately no details were provided about this. All but one of the nine courses used explicit written criteria for assessing candidates in interviews, though there was wide variation in the total number of people candidates are interviewed by (3 – 13). Most candidates were interviewed for a total of between half an hour and an hour.

**Question 13:** Please rate, with regard to personal qualities, the extent to which you believe your interview to be (0 = Not at all; 10 = Completely):

A valid procedure (it accurately assesses what it purports to assess)?
Mean = 6.8  Range: 5-8

A reliable procedure (it consistently assesses what it purports to assess)?
Mean = 7.33  Range: 5-8

A fair procedure (it is equally valid for all candidates)?
Mean = 7.66  Range: 5-10
Question 14: In the past five years, how many trainees have you accepted onto your course who you later believed to be unsuitable to become clinical psychologists, for reasons of personal qualities?

Mean = 1.33  Range: 0-5  Total = 12

Question 15: If you had a free hand to set up a new selection procedure, what would it involve? (6 courses responded to this item)

- I would certainly keep the interview format
- Inclusion of a group task. Selection takes up significant time and resources at the moment. Undoubtedly improvements could be made but the issue is one of cost-effectiveness.
- Have considered this several times over the last few years and if given free hand I would perhaps acknowledge that there is limited purpose other than trying to eliminate "unsuitables" and might therefore be less focused on academic issues at interview, or some personality assessment. However strong suspicion many could fake positive.
- The procedure evolves and a fresh look is possible and carried out each year. Seems to be a 'good enough' system. We have contemplated using psychometric assessments from time to time but so far they received little support for supervisors.
- I like our system. At interview we have two of our course staff with a regional representative. Our preference is to take students with a strong academic background.
- In true psychological fashion, we have three assessment panels for selection and require agreement from all selectors, so answering questions about "the interview" is inaccurate. Given time constraints etc I think it is reasonable procedure and our annual feedback suggests candidates find it fair
Abstract

The diagnosis and treatment of cancer is a highly stressful event and frequently leads to high levels of psychopathology among both patients and their partners. Social support, especially partner support, has been shown to act as a powerful buffer against the effects of stress including the stress of cancer. Theoretical and empirical work supports the contention that where the stressor, like cancer, is outside the individual's control, emotional empathic support is the optimal form of social support. However, a number of studies have suggested that while partner support can be an important source of social support, partners can sometimes be an additional source of stress to the patient, particularly among female patients. To date, almost all research examining partner support in cancer has examined female breast cancer patients and there have been no reported interventions designed to enhance couple support.

This study therefore examined gender differences in the ability of partners to communicate emotional and confiding support, and to evaluate in a randomised controlled trial the effectiveness of a video intervention designed to enhance couple support. 80 couples, in which one partner was suffering with a first diagnosis of colorectal cancer, were invited to participate of whom 46 couples consented. After both partners had independently completed questionnaires measuring demographic, communication, relationship and psychological variables, the couple was randomly assigned to the video intervention group or the standard care (no video) control group. Both groups were assigned equal numbers of male and female patient couples. Couples assigned to the video group were instructed to watch the video and discuss its contents together. Three months after randomisation all couples were reassessed on the same measures.
Results indicated that men perceived their partners to be significantly more empathic and supportive than women perceived their partners, while there were no significant differences in perceived criticism and withdrawal. The video appeared to have very limited effects on the couples who saw it though the sample size may have been too low to detect differences. The results are discussed with reference to their theoretical implications and the methodological shortcomings of the research.
PROMOTING COUPLE SUPPORT IN CANCER

1. INTRODUCTION

One in three people in the UK develop cancer in their lifetime and one in four people will die from it (Cancer Research Campaign, 1989). In addition to being a very common disease, cancer is associated with a high incidence of psychological distress and disorder (Massie and Holland, 1990) which poses a profound challenge to the small but growing field of psychosocial oncology (Maguire, 1995). It would be unrealistic to assume that there will ever be sufficient clinical resources within the National Health Service to meet this level of need. What is urgently required is a better understanding of the psychological processes which lead to these clinical disorders, and some empirically validated ways of preventing them from developing.

The diagnosis of cancer, for almost everyone, is a traumatically stressful event that precedes the rapid onset of a bewilderingly complex medical treatment involving a combination of surgery, radiotherapy, chemotherapy and/or hormone treatments. For many, it is the start of a personal ‘cancer journey’ that often takes several months to complete, during which time the individual may have to make dramatic changes in their lifestyles and role relationships. In view of the stress of these many changes, and the uncertainties surrounding this life-threatening illness, it might seem intuitively unsurprising that so many people develop high levels of anxiety and depression warranting psychological intervention. Although a considerable body of work over the past twenty years supports the conclusion that psychological treatment interventions can be effective in reducing psychological distress and improving quality of life (Sheard and Maguire, in press) as yet there has been less emphasis on the more pressing issue of preventing psychological suffering.
Between 15 and 20% of cancer patients will develop moderate to severe psychological disorders requiring mental health intervention. A further 30% will have an adjustment disorder involving symptoms of anxiety or depression (Massie and Holland, 1990). In addition, there is growing evidence that the families and carers of cancer patients face considerable psychological distress (Kissane, Bloch, Burns et al, 1994; Glasdam, Jensen, Madsen and Rose, 1996) and that both patients and spouses experience an erosion of social support in the months following diagnosis (Northouse, Templin, Mood and Oberst, 1998). This is important in view of the fact that perceived lack of support from family members (Neuling and Winefield, 1988), and from partners in particular (Weisman and Worden, 1976; Pistrang and Barker, 1995), has been positively related to anxiety and depression in cancer patients.

The following review will show that social support and, in particular, partner support, is highly relevant to the prevention of psychological distress among cancer patients. It will attempt to locate the specific issue of spousal support in cancer within the broad fields of social support, interpersonal relationships and care. It will also try to draw out some of the conflicts and complexities of the couple relationship when one member has become defined as the patient and the other the carer.

1.1 Social Support and Stress

John Cassel was one of the first scientists to empirically demonstrate a relationship between interpersonal ties and health. He hypothesised that social support might act as a buffer against the effects of stress (Cassel, 1974). Building on Cassel's work, Caplan (1974) conceptualised social support as a protection against pathology and characterised it as consisting of

"significant others who help people mobilise their psychological resources in order to deal with emotional problems... in order to help them deal with the particular stressful situation to which they are exposed."

(Brownell and Shumaker, 1984, p.2)
In the 25 years since Caplan’s definition, the social support literature within social and health science has burgeoned, and his definition has required elaboration. More modern definitions stress that social support is an interaction that may be both enacted and/or perceived. For example, it has been defined as “social interactions that provide individuals with actual assistance and embed them into a web of social relationships perceived to be loving, caring and readily available in times of need” (Kaniasty and Norris, 1997; p.595)

From a sociological perspective, social support has been viewed in terms of the degree of one’s social integration and the size and structure of one’s social network (e.g. Buunk and Hoorens, 1992). This is commonly known as the Main Effect hypothesis (Cohen and Wills, 1985); main-effect processes are thought to operate regardless of stress levels.

Cohen and Wills (1985) have suggested that, as a buffer against the effects of stress, social support serves four basic functions:

**Esteem support:** assures people that they are competent and accepted, despite their shortcomings, with the effect of bolstering their self-esteem.

**Informational support:** provides people with information or advice in order better to understand and cope with what is happening.

**Social companionship (or network support):** involves spending time with people in leisure activities, thereby reducing stress by fulfilling a need for affiliation

**Instrumental support (or tangible aid):** provides concrete assistance in the form of financial aid, needed services and other material resources.
Cutrona and Russell (1990) have added a fifth function which is closely related to esteem support: **Emotional support** provides comfort and security in times of stress, leading the recipient to feel cared for by others.

Social support has important parallels with the field of coping. In fact it has been argued that any (material, psychological or social) resources deployed to deal with life stress are always either support or coping. If the resources are governed by the person under stress they are part of the coping process; if they are governed by someone else, they are part of social support (Leatham and Duck, 1990). Indeed, Thoits (1986) has argued that social support is a form of coping assistance.

**THE MATCHING HYPOTHESIS**

Cohen and Wills (1985) have pointed out that, in order for the buffering effect to be observed, there must be a reasonable match between the type of support provided and the coping requirements of the stressor. This has since been variously termed the ‘matching hypothesis’ or the ‘specificity model’ (Trickett and Buchanan, 1997).

Although epidemiological research has led to some important findings, e.g. that people with social ties live longer and have better physical and mental health than those without such ties (Dunkel-Schetter, 1984), this approach has largely failed to further scientific understanding of optimal matches between types of stress and types of support. Furthermore, there has been conceptual confusion in the literature over how social support should be defined and operationalised, and too often it has been viewed along a single dimension. Furthermore, conclusions about social support have been largely based on correlational data collected at a single point in time (Wortman and Dunkel-Schetter, 1987).

Since the early 1980’s, however, there has been greater interest in regarding social support as a transactional process involving the stressor, the distress...
caused, the environmental conditions, the personal characteristics of the recipient and the provider, and the effect that these variables have on one another over time (Shinn, Lehmann and Wong, 1984); the implication is that social support may only be effective where there is an appropriate match between these variables. In particular, social support is seen as involving a complex interaction between the person receiving the support and the person giving it (Buunk and Hoorens, 1992) yet, until recently, there has been little dialogue between the fields of social support and personal relationships (Duck, 1990). Thus, more modern definitions of social support reflect its multidimensional and dynamic nature; for example, social support is seen as “an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (Shumaker and Brownell, 1984, p.13).

Using a cognitive appraisal model of stress, Cutrona and Russell (1990) have described a taxonomy of stressful events. These dimensions have implications for the type of support that is most beneficial in a given situation. For example, the controllability of an event predicts whether the individual will use emotion-focused or problem-focused coping. Controllable events are met with coping attempts to alter the distressing situation (e.g. advice, information, actual assistance, etc.), while uncontrollable events (such as cancer) will require social support components that serve to diminish the intensity of the emotions produced by the event (e.g. opportunities to ventilate emotions, re-evaluate the severity of one’s loss and “experience positive emotions that derive from sources not lost because of the stress (e.g., reminders that one is loved)” (Cutrona and Russell, 1990; p. 329)

1.2 Social Support and Adaptation to Cancer

Reviews of the literature on social support and adaptation to physical illnesses (Wortman and Conway, 1985) and cancer (Wortman, 1984; Wortman and Dunkel-Schetter, 1987), make similar methodological criticisms to those mentioned above. Although there has been broad acceptance of the fact that
social support positively influences health outcomes, including physical health (Wallston, Alagna, DeVellis and DeVellis, 1983) and even, more contentiously, survival in cancer (e.g. Maunsell, Brisson and Deschênes, 1995), most early studies used cross-sectional, retrospective or case-control designs, often using vague definitions of social support. Wortman and Conway conclude that what is needed is more longitudinal research examining distinct aspects of social support as predictors of subsequent health status, while controlling for other variables which are likely to have an impact on health.

While acknowledging that debilitating medical illness such as cancer can adversely affect all aspects of an individual's life (and so necessitate multiple forms of social support), Cutrona and Russell (1990) have categorised this type of stress as a negative, uncontrollable event that involves the loss of or threat to physical assets (including a threat to life). Thus, according to their model, emotional support and emotion-focused coping should be essential.

Drawing on interviews with 79 breast and colon patients (86% women; 62% married; mean age 56) 7 to 20 months after diagnosis of primary cancer, Dunkel-Schetter (1984) offers support for the idea that the uncontrollability of cancer engenders a need for emotional support above all other forms of social support. She found that 81% of her sample mentioned emotional support as one of the most helpful form of support, 41% mentioned informational support (if provided by health care staff) and only 6% mentioned instrumental assistance. She also found that the quantity, strength and satisfaction with support was significantly correlated with positive affect and self-esteem, though this association was only found among those with good prognoses.

Interestingly, some of the most unhelpful behaviours concerned family or friends giving the patient information and advice. Subjects were asked about nine statements presumed to be unhelpful. Of these the most frequently endorsed were "minimising problems or feelings about the cancer" and "being told not to worry because things would work out all right", each endorsed by 37% of
the sample. 87% of the sample indicated that they had coped by sometimes keeping their thoughts and feelings to themselves, largely because of their expectations of others' reactions. Furthermore, 28% of the sample felt that their spouses or significant others did not really understand their feelings about the cancer.

In her review of the literature, Rowland (1990) concluded, like Dunkel-Schetter, that positive social support is an effective buffer against the psychological distress of cancer, but that the loss of a significant other, who withdraws during the patient's illness, may become a more powerful stressor than the illness itself. These two overlapping issues will be addressed separately. However, as will become evident, most of the published studies on social support and cancer have involved breast cancer patients.

In one of the earliest published studies on this issue, Bloom, Ross and Burnell (1978) provided 21 women who had had mastectomies with a support intervention that included information, opportunities for emotional expression and support from medical and mental health professionals. Two months after their mastectomies the women who received this intervention had higher self-esteem and self-efficacy scores than women who did not. Although being of potential interest, being virtually the only published account of a social support intervention in cancer, this study demonstrated the efficacy of support by professionals but not the patients' own social network.

The effect of family support, however, was demonstrated in a study of psychological adjustment of 54 women with metastatic breast cancer (Speigel, Bloom and Gottheil, 1983). Patients who reported at baseline that their families were high in expressiveness and low in conflict tended to show less mood disturbance over the course of the year following their diagnosis. The authors speculated that families high in expressiveness may provide an opportunity for the sharing of fear and frustration, thereby making it a mutual concern rather than one that the patient must endure alone.
Neuling and Winefield (1988) reported a longitudinal study of recovery after surgery for breast cancer, in which 59 patients (35 of whom had had a mastectomy) reported the frequency of, and satisfaction with various supportive behaviours by specified family members (39 of the 43 married patients nominated their husbands) and friends. These behaviours were those first explored in the Dunkel-Schetter (1984) study described above. The women were interviewed 2-7 days after their breast surgery and were followed up one and three months post-surgery in their homes or by postal questionnaire. The results confirmed Dunkel-Schetter’s finding that cancer patients require and obtain significant amounts of empathic support from family members yet do not look for information or advice from this quarter. Emotional support appeared to be abundantly available, compared with other types of support from family members, around the time of the operation, decreasing in a linear fashion over the next three months. However, in spite of this, empathic support was most widely criticised as being insufficient. Satisfaction with family support was highly related to low scores on anxiety and depression in the early stages following surgery but this relationship appeared to decline at the one-month post-operation time point.

Other studies confirm the importance of social support to overall emotional adjustment following diagnosis. Generally those with more social support and greater satisfaction with this support demonstrate less anxiety and depression over time (Northouse, 1988; Rodrigue, Behen and Tumlin, 1994). A number of authors have pointed to the importance of spousal support to the well-being of married or cohabiting patients (Neuling and Winefield, 1988; Rose, 1990). This issue will now be explored.

1.3 Partner Support

Among social relationships, marital status has been the most studied and most consistently related to health, though the benefits are almost always greater for men than for women (House and Kahn, 1985). One of the most important
positive health effects of being married appears to be through its transaction of 
social support, usually by involving people in a greater number of family ties and 
social networks, and by preventing social isolation (Baider, Kaufman, Peretz, et al, 1996). Studies have shown that when people have an emotional concern 
they are most likely to turn to their spouse or partner for support (Barker, 
Pistrang, Barker and Shaw, 1990), and, indeed, the lack of a confiding 
relationship increases the risk of depression. Among the partner/carers of 
people with cancer, one study has shown that 76% of male and 56% of female 
partners viewed their spouses (i.e. the patient) as their predominant source of 
support (Keller, Henrich, Sellschopp, and Beutel, 1996).

Unfortunately, however, neither the Main Effect model nor the Stress-buffering 
model clearly accounts for how interpersonal relationships either help or hinder 
adaptation within the system of spousal support (Baider, Koch, Esacson, and 
Kaplan De-Nour, 1998). One of the methodological challenges in examining 
the relationship between partner support and health is its interactional nature, 
with both variables affecting the other (Burman and Margolin, 1992). 
Furthermore, studying the relationship between psychological morbidity and 
partner support is unlikely to be fruitful unless the quality of the interactions 
between patient and partner are considered in detail. For example, as has been 
demonstrated in several of the studies discussed below, problems in a 
relationship may be a more powerful influence on emotional well-being than the 
positive aspects of the relationship. Prevalence of depression among single, 
separated or divorced people is three times higher than in those who are 
happily married; however, those reporting marital dissatisfaction are 25 times 
more likely to be depressed than single people (Schulz, Schulz, Schulz and von 
Kerekjarto, 1996).

There have been a number of cross-sectional studies to indicate that being in a 
close relationship predicts better psychological adjustment to cancer (Shag, 
to be an especially rich source of emotional support at times of stress and may
be more sensitive than others to the plight of the patient and their particular needs (Bolger, Foster, Vinokur and Ng, 1996). However, like patients, partners demonstrate high levels of distress following the diagnosis of their partner's cancer (Kissane, Bloch, Burns et al, 1994) and in one study of prostate cancer patients, the partners' demonstrated significantly higher levels of distress than the patients (Kornblith, Herr, Ofman et al, 1994).

A Danish study of 102 mixed-site cancer patients' spouses (65% female) reported that 18% had scores on the Hospital Anxiety and Depression scale that were indicative of a clinical disorder while a further 32% were borderline (Glasdam, Jensen, Madsen and Rose, 1996). Interestingly, although spouses reported that their contact with family and friends had been maintained or even intensified, only a third reported feeling any support from these sources. This is a potentially important finding since it is likely that people who are well supported are better able to give support. The fact that spouses may be as distressed as patients has led some authors to question their ability to provide support (Baider et al, 1996). However, the critical question is whether the partner's attempts at support are perceived as supportive by the patient, a question which has rarely been examined in the literature, and whether anything can be done to mitigate partners' distress. In one study of 121 husbands of breast cancer patients, self-reported close confiding relations with their wives was associated with better emotional adaptation, as was the opportunity to share closeness and discuss feelings with other adults (Hoskins, Baker, Budin, et al, 1996). The implication of this may be that partners should be encouraged to diversify their sources of support.

Two investigations have attempted to track the psychological congruity of patients and their spouses, and both have noted a high correspondence between partners over time. Northouse studied 58 couples where the woman received a diagnosis of breast cancer and 73 couples where the woman had a diagnosis of benign disease (Northouse et al, 1998). Couples were assessed "a few days after their diagnosis", and 60 days and 1 year post-diagnosis. Not surprisingly,
couples in the malignant group reported significantly more emotional distress than those in the benign group. Women in the malignant group perceived a linear but slow decline in the support they received over the course of the study while the men in this group experienced a dramatic drop in support at the 60 days point, perhaps, as the authors suggest, because they had been perceived by others as care providers rather than people in need of support themselves.

The other prospective study (Omne-Pontén, Holmberg, Sjödén and Bergström, 1995) interviewed 56 breast cancer patients and their partners separately at four and thirteen months after surgery. This study sought to examine whether the husband was able to perceive accurately his wife’s needs and provide the support required, and whether this was predictive of her later psychological adjustment. Over 90% of the couples had been married for more than 10 years. The authors found that both patients’ and husbands’ assessments (in semi-structured interviews) of the marital relationship at four months were significantly related to the patient’s later psychological outcome. However, the authors noted that despite assertions of having a ‘good’ marital relationship, some spouses (both men and women) reported avoiding talking about their concerns in order to protect their spouse from further anxiety, and some of the women were convinced that “only another woman” could give them the kind of empathy and support that they needed.

1.4 Impact of Chronic Illness on Partner Relationships

Although the psychological benefits of a supportive partner relationship are apparent, a number of authors have alluded to problems that may develop in the relationship between the recipient and provider of care and support. For example, studies of informal helping and support among healthy subjects have shown that partner helpers are more inclined to use advice-giving, interpretation and self-disclosure than stranger helpers (someone unfamiliar to the recipient) (Barker and Lemle, 1987). Spouses were more inclined to try to change their partner’s behaviour rather than explore their feelings, and thus were rated as showing less empathy than strangers in the same position.
Several researchers within the field of personal relationships have called for a greater collaboration between their field and that of social support, arguing that it is within the domain of personal relationships that social support is delivered (Coyne and Smith, 1991; Leatham and Duck, 1990; Hatchett, Friend, Symister and Wadhwa, 1997). As has been observed, relationships are not the product or sum of two pre-formed minds but also a reflection of the evolving relationship and its social context (Duck, West and Acitelli, 1997).

Leatham and Duck (1990) have described several ways in which a relationship may be strained by the giving and receiving of social support. For example, unrelenting painful disclosures and depressed or needy communication can have a wearing effect on the recipient. If previous attempts at support have had negative consequences, the recipient may devalue and criticise the present support attempt. In addition, the provision of social support can do as much to destabilise a relationship, as the relationship can do to stabilise a person under stress (e.g. changes in role relationships). The authors argue that both fields need to pay closer attention to the mundane “daily dynamics of relating and also to the talk through which relationships – the basis for support – occur” (p.22). The following studies demonstrate some of these points.

At its simplest level, cancer appears to have negative long-term consequences for some marriages: marital tensions and strains are reported to occur in 10 to 20% of couples affected by cancer (Keller, Henrich, Sellschopp, and Beutel, 1996). For example, 403 survivors of Hodgkin’s disease were surveyed about various health and psychosocial variables on average nine years after their last treatment (Fobair, Hoppe, Bloom, Cox, Varghese and Speigel, 1986). 129 (32%) of the total sample were divorced and, of these, 69 had been married at the time of their diagnosis. 34 (49%) of these 69 attributed their divorce to their Hodgkin’s disease. Although unreliable due to its retrospective nature, this is a striking finding.
In addition to the stigma and avoidance of others, cancer patients may experience diminishing support with time. In an examination of 100 breast cancer patients and 100 male and female disease-free individuals, Peters-Golden (1982) reported that healthy individuals showed high levels of stigma and avoidance towards cancer patients yet imagined that they themselves would have an extensive network of support to draw upon if they developed the disease. Importantly, 38% of those with recurrent disease (55 out of the 100 patients) reported that the support they received from others was inadequate, yet this was the case among only 11% of those with no recurrent disease. This suggests an erosion of support from first to recurrent diagnosis, though it is likely that recurrent disease also engenders a greater need for emotional support.

The damaging effect of problematic relationships on psychosocial adjustment was examined in a prospective survey of 68 end-stage renal disease patients (Hatchett, Friend, Symister and Wadhwa, 1997). Results confirmed that patients' perceived inability to meet others' expectations about coping with their illness were predictive of more psychological distress. In fact, the authors concluded that abating interpersonal conflict may be a more productive strategy in preventing distress than simply mobilising social support.

As well as patients having to cope with the perceived expectations of others, there is evidence that chronic illness may lead spouses to be critical of the patient. Manne and Zautra (1989) interviewed the husbands of 103 women with rheumatoid arthritis who also completed questionnaires on the burden of caring for their wives. The women separately completed a coping scale and a questionnaire concerning the perceived supportiveness of their spouses. Although cross-sectional in design, the results of this study indicated that positive support from husbands led patients to engage in more adaptive coping behaviours, such as cognitive restructuring and information-seeking efforts, while critical remarks from husbands appeared to lead to ineffective or harmful coping strategies such as wishful thinking (e.g. about a cure) with negative
effects on self-esteem. As mentioned above, one purported causal mechanism underlying the effectiveness of social support is that it may influence coping indirectly by enhancing the recipient's self-esteem (Wortman and Dunkel-Schetter, 1987). Reasons for the critical behaviour of husbands were not clear though there was some evidence that they resented the fact that their wives' illness imposed limitations on their social, recreational and sexual activities.

Wortman and Dunkel-Schetter (1987) have succinctly summarised some of the main communication problems for cancer patients:

"Although their feelings about the patient's illness are largely negative, others appear to believe that they should remain optimistic and cheerful in their interactions with the patient. This conflict ... may result in physical avoidance, avoidance of open communication, and strained interaction. The person with cancer often interprets these behaviors as evidence of rejection at the very time when support from others is especially important." (p. 67)

There is ample evidence that many people with cancer value opportunities to express their fears and anxieties about recurrence and death (e.g. Lichtman, Taylor and Wood, 1988), though other data suggests that people tend to turn away from people under stress (Buunk and Hoorens, 1992). Indeed, they may disparage the distressed person as a way of dealing with their own perceived incompetence at support or sense of personal failure (Berrenberg, 1989), though they may be more inclined to help if they believe that such help will be productive and lead to real improvement in the lot of the recipient (Silver, Wortman and Crofton, 1990). Some authors have suggested that support may even decrease patients' morale and sense of control if it leads to a reinforcement of their perception of incapacity (Bolger, Foster, Vinokur and Ng, 1996), while others have argued for the importance of open communication in relationships which fosters cohesion, increased marital satisfaction and psychological adaptation (Keller, Henrich, Sellschopp, and Beutel, 1996).
Some evidence for the erosion of social support over time has already been presented (Dunkel-Schetter, 1984; Neuling and Winefield, 1988; Northouse et al, 1998; Peters-Golden, 1982). Bolger et al (1996) reported data which specifically focused on how significant others withdraw support in response to patients' emotional distress. They studied 102 newly diagnosed breast cancer patients and their significant others four months and 8-10 months after diagnosis. The spouses of the patients who were married (73%) were also interviewed as well as the remaining significant others who comprised daughters (17%), friends (7%) and siblings (2%). Results indicated that over the six month period of the study patients' physical impairment had the effect of mobilising the support of the significant other, but the patients' distress also had the effect of eroding this support. Furthermore, the support that was delivered appeared to be ineffective in reducing distress or promoting physical recovery.

The authors speculated that a “contagion of distress” from the person under stress to the supporter may have led to an erosion of support. Although they had little data to support their claim, they argued that one explanation might be that significant others regard physical impairment as beyond the patient’s control, thereby meriting their support, whereas they regarded the patient’s emotional distress as controllable and thus less worthy of support. They concluded that both parties need to develop an awareness of the difficulties faced by the other, a position central to the current research described below.

Focussing on the communication behaviour of support providers, Pistrang and Barker (1992) studied 77 women with recently diagnosed breast cancer, to discover who they turned to for emotional support. They found that 51% of those who had a partner (61% of the sample) regarded their partner as their ‘most important helper’. However, 38% of those who had nominated their partner as their preferred helper prior to breast cancer no longer regarded him as their preferred helper. The authors noted that women reported more problematic communication with partners than with friends and relatives. In
particular, they withheld talking to their partners but would like to have talked more. They also felt less understood by partners and found talking to them less helpful than friends or relatives. Pistrang and Barker concluded that their data suggest that “the communication problems with partners were more to do with men’s difficulties in dealing with feelings, rather than an inability to understand the women’s concerns.” (p. 190)

Pistrang and Barker (1995) subsequently reported cross-sectional data on a larger sample (N=113; 60% married), which included that of their former study. Using subscales from the Symptom Check List (SCL-90R) and the Profile of Mood States (POMS-BI), they found that satisfaction with the partner helping relationship was associated with psychological well-being. Good communication with the partner was characterised by high empathy and low withdrawal, though women with partners were generally more distressed than women without partners. These authors also found that support from relationships outside the partner relationship did not compensate for the lack of a confiding relationship with the partner. They concluded that a poor partner relationship appears to be a risk factor in women’s psychological responses to breast cancer. The value of confiding emotional support to positive adaptation to illness has been further confirmed in another cross-sectional correlational study of breast and prostate cancer patients undergoing radiotherapy (Gotcher, 1992).

Finally, one study, which again showed negative partner behaviour having a significantly deleterious effect on psychological outcome, was unique in measuring the relationship between both positive and negative partner behaviours (Manne, Taylor, Dougherty, and Kemeny, 1997). In this cross-sectional study, it was hypothesised that negative spouse responses (withdrawal, avoidance and critical remarks) would be a more potent predictor of psychological outcomes than positive responses. It was also predicted that spouses who were critical and avoidant would also engage in fewer positive responses. 158 married individuals (88 male, 70 female) with cancer (colorectal: 101; breast: 27; other sites: 30) were studied while receiving treatment (68%
had metastatic disease). Measures, administered two months after the start of
treatment, included perceived supportive spouse behaviours, perceived negative
spouse behaviour, a mental health inventory and a measure of functional
disability.

Results indicated a gender difference with respect to withdrawal behaviours, with
female patients perceiving significantly more withdrawal/avoidant responses
from their husbands. They also reported more psychological distress than the
male patients. Of particular interest was the finding that for male patients,
perceived supportive and perceived negative behaviours of their partners were
independent. However, for female patients, the greater the social support
provided by their husbands, the less likely they were to be perceived as critical
or avoidant. For male patients, perceived supportive behaviours were not
significantly associated with psychological outcome but, for female patients,
perceived support was associated with higher scores of well-being.

The authors conceded that their measures of support may not have tapped into
the most relevant aspects of social support such as empathy or understanding,
and that “future studies need to further examine gender differences in spouses’
responses to illness” (p.118), but they concluded that, on the basis of their data,
it appeared that negative behaviour within close relationships has a stronger
association with mental health than positive behaviour.

1.5 Gender and the Burden of Care

Most caring in Western society is performed by women. For example, Orbell
(1996) has reviewed the literature on the caring of elderly people and has
reported that in most epidemiological studies about 70% of carers are women.
One explanation for this has been that, because of the more restricted
employment opportunities for women, there is less “opportunity cost” of giving
up work to look after an elderly relative. Another is to do with filial obligation,
though this does not explain why it is women as opposed to men who so often
provide the bulk of care in a family. However, an alternative view is that caring
is 'women's work' and that this gender role is socially reinforced. Orbell presents some evidence that, as a result of socialisation, nurturant and relationship skills are central to girls' and women's self-concept, a view shared by others (e.g. Gilligan, 1982). Thus, failure to engage in care may be more threatening to a woman's self-concept and result in more feelings of guilt than they would in a man.

A recent review of the impact of caring for cancer patients on the care-giver has concluded that little is known about changing patterns of care-giving in relation to the course of the illness (Nijboer, Templaar, Sanderman et al, 1998) yet this is clearly a central question in a disease which is increasingly becoming defined as chronic. This review notes that the type of help provided may be a more important predictor of burden on the care-giver than the total number of tasks or time taken in care-giving. Personal tasks (such as feeding and washing the patient) are considered more burdensome, particularly if they restrict the freedom of the care-giver (see Manne and Zautra, 1989, above) than non-personal tasks (such as doing the shopping) while emotional support is considered one of the most stressful aspects of the role. As has already been noted, the emotional distress of the patient may erode the provision of social support.

The relationship between gender and the distress of patients and spouses is not yet clear though there is considerable evidence that females, whether patients or care-givers, face greater burden and psychological distress than men (Baider, Koch, Esacson and Kaplan De-Nour, 1998; Burman and Margolin, 1992; Nijboer, Templaar, Sanderman et al, 1998). For example, in a study of care-giving in advanced cancer, Stetz (1987) reported that women expressed a greater need to stand by their ill husbands and reported more care-giving demands than did men in the equivalent role. As has been mentioned above, a study of prostate cancer patients found that their wives demonstrated significantly higher levels of distress than the patients themselves (Kornblith, Herr, Ofman et al, 1994).
In one of the few prospective studies comparing men and women as both patients and spouses coping with gender-neutral cancers (colon, stomach, melanoma and lymphoma), Baider et al (1998; Baider et al, 1996) examined 67 couples (28 female patients) at four time points over a 2 year period following initial diagnosis. All participants were interviewed in their homes and given questionnaires measuring family cohesion and adaptability to role changes, and psychological distress. Results (reported only for time points 1 and 4) indicated that both patients and spouses were moderately distressed at both time points, with women reporting higher distress scores at T1 than their partners whether they were the patient or the partner (though this effect only reached statistical significance when the women were the partners). The psychological distress of women, whether sick or healthy, was significantly influenced by the distress of their husbands, while the psychological distress of men was only slightly influenced by the distress of their wives.

It is likely that men and women have different coping strategies in the face of stress, whether they or their partners are the primary victim of the stress. For example, Billings and Moos (1981) conducted a survey of 200 families in the San Francisco area and assessed their coping with a life event or personal crisis occurring in the previous year. Although husbands and wives used more problem-focused coping methods than emotion-focused methods, women reported using significantly more emotion-focused coping than men. Consistent with the matching hypothesis, discussed above, subjects used less problem-focused coping when the stress involved a death in the family (an uncontrollable stressor) than when confronted with other sources of stress.

More direct evidence for the difference between men and women in the way they cope with the role of being a carer comes from a study of spouses of mastectomy patients (Sabo, Brown, and Smith, 1986). In this study men were found to be emotionally engaged with their wives' distress but were hiding it, preferring to play a more 'positive', protective, reassuring and minimising role.
However, their wives interpreted this as insensitive and rejecting. This is similar to Pistrang and Barker's (1992) results discussed above. Another investigation compared women's and their husband's distress prior to the woman's biopsy for possible breast cancer (Northouse, Jeffs, Cracchiolo-Caraway, et al, 1995). Typically, the husbands reported considerably less distress than the women and did not discuss the biopsy with friends or co-workers but limited their discussion to wives and family members. Again, these responses were thought likely to reflect gender role differences in society at large, in that men may be more likely than women to confide solely in their partners.

Gender roles were examined in research on recently married healthy couples which measured marital satisfaction and depressive symptoms at two time points, eighteen months apart (Fincham, Beach, Harold and Osborne, 1997). Results were analysed using structural equation modelling. As in previous research, marital satisfaction was inversely related to depressive symptoms. However, the more interesting finding was that there were different causal pathways for men and women. The causal path from marital satisfaction to depression was significant for women and the causal path from depression to marital satisfaction was significant for men. The authors indicate that the results are consistent with previous research suggesting that "men may respond to their own depression by denigrating their relationships or by withdrawing from relationships to a greater extent than is true for women" (p. 356). Women, meanwhile, may be more vulnerable to marital stressors than men because they feel, or are required to assume, more responsibility for the resolution of relationship difficulties (Gilligan, 1982). If true, this finding has implications for the caring role among men and women: for example, if men experience a sudden reduction of emotional support (from its primary source – their wives) when they are forced to care for their wives, they may respond with criticism or withdrawal.

Gender differences in supportive care are also evident in a study examining the changes in household responsibilities in 27 Canadian families over the course of
the mother’s treatment for breast cancer (Green, 1986). Unusually, data was collected in family interviews which may have had the result of family members understating the effects reported. The family was asked to comment on each of the questions put to them and generate a number along a given scale that best reflected their consensus. Two interviews were conducted, six weeks post-diagnosis and 6 to 12 months later. The first interview also collected retrospective data on household activities prior to the diagnosis. Of the 27 families, 9 mothers were ‘non-partnered’ but all families contained children. Among the partnered families, most of the responsibility for most household activities was carried by the woman before, during and after her cancer. For five activities (shopping, housework, co-ordination of children’s activities, childcare and clothing upkeep), in which the woman had carried in excess of 50% of the responsibility prior to her diagnosis, her responsibility dropped by 15-35% while she was in treatment. However, at the second interview, only a few months after her diagnosis, responsibility distributions had returned to, or in most cases exceeded pre-diagnosis levels. In both partnered and non-partnered groups, women maintained considerably more responsibility than they relinquished for household responsibility including caring for the material needs of others in the family. Other studies have found that wives shoulder a greater housework burden that men and a disproportionate share of responsibility for maintenance of the family organisation and the provision of nurturing regardless of whether they are patients or spouse care-givers (Baider, 1995; Baider et al, 1998).

Finally, conversation analysis research has examined the helping process that occurred between 26 women with breast cancer and two different types of helper: the woman’s male partner and a fellow breast cancer patient (who had completed her treatment for breast cancer) (Pistrang and Barker, in press). Building on Barker and Lemle’s (1987) work on partner vs. stranger helping behaviour, mentioned above, this study used trained observers to rate the communications between the woman and her helper. Results found that the ex-patient helpers were rated as more helpful, empathic and supportive, less critical
and as using more self-disclosure than the partners, with no differences in problem-solving or exploration. From the observer's point of view, the helpfulness of the partner was negatively associated with criticism and the helpfulness of the ex-patient was negatively associated with self-disclosure. However, interestingly, the women did not differentiate between the two helpers, regarding both as helpful. The authors refer to work suggesting that women may be more skilful in supportive interactions while men are more inclined to take a problem-solving approach, consistent with the data from Billings and Moos (1981) referred to above.

1.6 Summary and Conclusions

The diagnosis and treatment of cancer is a highly stressful experience both for the ill person and their partner, and frequently leads to high levels of psychological morbidity. Social support, and particularly partner support, can act as a powerful buffer against the effects of stress and this finding appears to hold true in the context of cancer where it has been shown to be an important factor in patients' psychological adjustment. However, social support is multi-dimensional and theoretical work points to the need to match the type of support provided with the type of stress being confronted. Since serious illnesses like cancer are experienced as out of the individual's direct control, theory predicts that emotional/empathic support should be the most effective in reducing distress. Empirical work appears to support this assumption.

People under stress are more likely to turn to their partner or spouse for support rather than others. However, social support and care can lead to strains and problems within the relationship between patient and carer which may, in turn, bring about an erosion of this valuable source of support and the development of subsequent psychosocial problems for either party. Partners often lack social support from friends and family and this may contribute both to their own psychological vulnerability and to their capacity to support the patient. Finally, there appear to be gender differences in the level of distress experienced
by men and women, both as patients and as carers, as well as differences in men and women's ability to demonstrate empathic care.

To date, almost all studies looking at partner support in cancer have examined breast cancer patients (Manne, Taylor, Dougherty, and Kemeny, 1997), all of whom have been women, rather than comparing the sexes in equivalent roles as patients and partners. Furthermore, most of these investigations have used cross-sectional rather than prospective designs. What remains unclear from the literature is whether there are differences over time in men and women's behaviour and psychological functioning when they are either in the role of patient or partner/carer. To answer this question would require all patients to be suffering with a gender-neutral disease such as colorectal cancer, leukaemia or lymphoma.

Furthermore, while there have been numerous reported interventions for cancer patients, no published study to date has evaluated a preventative clinical intervention with the specific purpose of promoting and enhancing partner support when one member of the couple has been diagnosed with cancer.

1.7 Research Aims

The present study has two aims.

1. To examine the differences between men and women in their abilities to communicate emotional and confiding support to their partners when one of them has cancer; to measure this perceived support and to measure the effect of this support on the psychological adjustment of both patients and spouses.

2. To devise and evaluate a preventive intervention designed to enhance the mutual provision of social support between patients and their partners.
1.8 Implications for an Intervention

The preceding review indicates that certain elements should be present in such an intervention:

1. In view of the high incidence of cancer in society and the scarcity of professional psychosocial support resources, the intervention must be cost-effective to deliver.

2. The intervention should emphasise the use of empathic/emotional support over more instrumental or informational types of support.

3. The intervention should aim to prevent some of the interpersonal communication difficulties that have been referred to in the literature (e.g. critical remarks, avoidance and withdrawal, partners minimising the patient’s distress or being overly positive about the disease, unreasonable expectations, etc.) and which may be an aspect of support erosion.

4. It should also aim to promote those interpersonal behaviours which have been reported as helpful: emotional ventilation, expressions of affection, mutual empathic sharing of concerns, etc. In short, it should encourage both partners to develop an awareness of the difficulties faced by the other, not assume that the other person should know what they are feeling, an observation noted by clinicians in the field (Moorey and Greer, 1989).

5. Partners of patients should be encouraged to seek out additional support for themselves in view of the fact that they may have temporarily lost the support of the patient (who is likely to have become preoccupied with their own predicament). In addition, there is evidence that partners do not receive adequate support from friends or relatives, possibly because they, and others, perceive partners as care-providers rather than in need of
support themselves. Without adequate support themselves, it may be
difficult for partners to provide support to the patient (Baider, 1995).

1.9 The use of video technology to promote behaviour change

The medium of video was chosen for its obvious potential cost-effectiveness in
such a prevalent disease as cancer. In 1996, 82% of British households
possessed a video player, a proportion which appears to be rising in a linear
fashion by about 2-3% per year (Thomas, Walker, Wilmot, and Bennett, 1998).
Eiser and Eiser (1996) have reviewed studies evaluating the use of videos as
health education interventions. However, they report no published studies in
which the aim of the video was to enhance social support. Most were
concerned with health education messages or preparation for medical
treatments. They point out that in spite of their enormous potential value, both
in terms of information delivery as well as skill transmission, few formal
evaluations have been undertaken of the many videos that have been produced.
Their review concludes that most of the studies demonstrated little or no positive
evidence for the effectiveness of video as a health education intervention.
However, this was largely because of particular problems that were common to
many studies:

1. Authors appeared to lack any clear notion of what effects to expect from
    their video and thus what variables to measure.

2. There was often a failure to develop the intervention with any
    involvement of the target group so as to match the content of the
    programme with the real concerns of that group.

3. Many videos lacked any underlying theoretical basis for behaviour change
However, videos appeared to have demonstrable advantages when used to present: (a) models of specific behaviour to be imitated and rehearsed; (b) information in an appealing way; and (c) information about the damaging consequences of behaviour. In fact, they reported that fear can be a powerful motivator for behaviour change, a view consistent with the Health Belief Model (Becker and Rosenstock, 1984) which was adopted as the theoretical backbone for the video intervention described below.

1.10 Hypotheses

1. That cancer patients, receiving an intervention designed to enhance partner support, will have lower levels of psychological distress than those who receive standard care alone.

2. That the partners of cancer patients, receiving an intervention designed to enhance partner support, will have lower levels of psychological distress than those who receive standard care alone.

3. That the intervention will improve the patient’s perception of the effectiveness, helpfulness and supportiveness of their communication with their spouse, and will lead to higher satisfaction with the relationship relative to the control group.

4. That patients’ perception of support and empathy from their partners will be associated with good psychological adjustment.

5. That males are more likely than females to perceive their spouses as their primary source of support in equivalent roles of patient or partner, and

6. That the intervention will lead more females to regard their spouses as their primary support.

7. That female patients will perceive their spouses to communicate lower empathy and supportiveness, and higher criticism and withdrawal than male patients.
2. METHOD

2.1 Design

This study was a randomised controlled trial, evaluating the impact of a video intervention on the psychological, communication and relationship functioning of couples in which one partner was being treated for cancer. See Figure A — Study Design.

Participating patients and partners were sent separate self-report questionnaires by post and instructed to complete them independently of one another before returning them to the experimenter. The couples were then randomised to one of two groups. The intervention group received a video, an accompanying leaflet and a short questionnaire (for both participants) concerning the video. The control group received routine care (i.e. no video). All participants were reassessed three months after randomisation. The sample size was not predetermined using a power calculation since an audit study had revealed that 323 married patients were newly diagnosed with colorectal cancer in 1996, suggesting that achieving a large sample size of at least 50 couples in both groups would not pose difficulties.

FIGURE A: Study Design
2.2 Participants

Participants were drawn from patients attending oncology out-patient clinics at the Bristol Oncology Centre, Musgrove Park Hospital (Taunton, Somerset), the Royal United Hospital (Bath, Wiltshire) and Yeovil Hospital (Somerset). All patients were heterosexual, married or co-habiting, and were newly diagnosed with their first occurrence (i.e. no recurrences) of colorectal cancer. Eligibility for the study required that neither the patient nor their partner had had any previous cancer illness, that the patient was under 80 years old, and that the couple had access to a video player. Finally, the patient’s expected survival, as judged by his or her oncologist, had to be at least one year.

COLORECTAL CANCER

Colorectal (bowel) cancer is the second most common cause of cancer in the UK, and was responsible for over 15,000 deaths in 1996 (c.f. NHS Centre for Reviews and Dissemination, 1997). The incidence rate of the disease (45 per 100,000 of the population) rises sharply with age and fewer than half of all patients survive more than 5 years. Of those afflicted 59% are men. Surgery is the first-line treatment and is given to over 80% of patients, while pre- and post-operative radiotherapy and chemotherapy do offer some survival benefit. All the patients in the current study were receiving either radiotherapy and/or chemotherapy.

2.3 The Intervention Video

In view of the lack of intervention studies targeting couples affected by cancer and the reported high incidence of psychological problems within the couple relationship, a video intervention was chosen because of its potential cost-effectiveness. The conception of the video was to weave both the personal testimonies and stories of patients with the advice of an “expert” (the author). The Health Belief Model (HBM) guided the making of the video in as far as the
author attempted to include the following four elements of the model and to make the desired behaviours as explicit as possible:

1. perceived susceptibility (the belief that one may be vulnerable to a particular threat, problem or disease)
2. perceived seriousness (the belief that the consequences of the threat, problem or disease are severe and noxious)
3. perceived benefits of preventive action (the belief that by engaging in the behaviour promoted by the intervention one will prevent the threat from occurring)
4. perceived barriers (the belief that barriers to preventive action can be overcome; i.e. self-efficacy)

The focus of the intervention was to promote empathic emotional support between both partners, to reduce unhelpful behaviours (such as withdrawal, being critical or being overly ‘positive’) and to avoid the erosion of support by encouraging the carer-partner to acquire further support for themselves. However, in accordance with the HBM, the video begins with several allusions to the threat of anxiety and depression if the subsequent advice is not followed. The video also emphasises that cancer affects both partners in a relationship, not just the patient, and that it is a stressful time for both of them. Thus, from the beginning, there is an attempt to validate the experience of the partner as well as the patient. Following the patients’ and expert’s anecdotal accounts, the video ends with clear prescriptive advice which summarises the behaviours that have been advocated in the video.

MAKING THE INTERVENTION VIDEO

The highly iterative process of making the video intervention will now be described because this process was intrinsic to the film that emerged. The video was made over a six month period with the assistance of a professional video maker who provided technical advice and did most of the filming using a hired
digital video camera. All directorial and editing decisions were made by the author in light of the many sources of feedback that emerged during the process described below.

Five former female patients of the author (all of whom had completed their treatment for cancer at least six months before) were invited by letter to participate in the making of the video. Subsequently, a male ex-patient was invited to take part in the video and, in accordance with his wishes, he was filmed separately on hospital premises. All participants provided their written consent (a) before being filmed and (b) several months later, after they had read the transcript of what the author was proposing to use in the film.

All the women were invited to spend a day making the film at the author’s house. The women were strangers to one another except for two who knew each other through a church organisation. A three hour discussion took place in the morning between all the women and the author concerning some of the issues that the author wished to draw out in the video. Although the author had chosen women who had had either positive or negative experiences of support from their partners, he was careful to make no allusion in the focus-group meeting to any information that had been acquired in his clinical work with the women. Thus, issues were raised in general abstract terms and it was left up to the women to elaborate on them as they wished, often resulting in very personal self-disclosures. It is regrettable that this meeting was not recorded in light of the powerful feelings it aroused and the processes of mutual identification and bonding that developed between several of the women. The camera crew joined the women and the author for lunch, after which filming began. While the first women were being filmed, others continued their discussions and further considered the points they wished to make on the video.

Note that a parallel film, designed to be used as a control intervention, was made simultaneously. This film, called Finding the Calm, was a twelve minute stress reduction intervention. Due to recruitment difficulties, this arm of the trial was dropped.
Following transcription of the raw footage of the patient testimonies, followed by rudimentary editing, the author was filmed (fulfilling the role of "expert professional") in order to draw out further points and to ensure that the video would not lead partners to feel excessively guilty over omissions of support on their part. It was felt important to emphasise that cancer affects both members of the couple and that the roles of patient and partner are both stressful.

There followed a more rigorous editing of the complete transcripts, and the writing of 'voice-overs' in order to ensure continuity and shape to the programme. 'Cut-away scenes' (visual analogues of the spoken material) were then filmed and the voice-overs recorded. The original footage, the cut-aways and the voice-overs were then taken to an off-line video-editing suite where they were compiled into an 'off-line' (i.e. semi-finished) version of the programme.

The off-line version of the video was then shown to two ex-patient cancer support volunteers, an independent video-editor, as well as numerous others for their feedback. After taking this feedback into account, the final edit list of the video (Appendix A) was sent to all ex-patients who appeared on the video in order to obtain their final consent. The final edit list was then taken to an 'on-line' video editing suite where, with music and titles, it was rendered onto a Betacam master. Multiple copies of the finished videos were subsequently made from this master over a number of days. The completed video is 15 minutes and 34 seconds long.

The prescriptive advice with which the video ends summarises the main themes discussed. These are:

1. "Anxiety and depression are less likely to develop if the couple are able to face the stress of cancer together"

2. "Try to be clear with each other about what you are feeling, but don't assume you know what your partner is feeling or thinking"
3. Do your best not to interrupt your partner when they are speaking; try to listen more than talk.

4. Avoid being critical of your partner; remember that it is a stressful time for both of you and that both of you need support.

5. Words may not always be as important as giving or receiving a hug from your partner.

6. Remember that being overly positive, giving advice, or finding a solution is not always what's needed; try to find out instead whatever your partner would find it helpful to talk about.

7. Don't worry about saying the wrong thing — the important thing is to try to stay involved.

8. Find someone else you can talk to, and get support from, on a regular basis.

2.4 Measures

A number of the measures were identical to those reported by Pistrang and Barker (1992, 1995) in their study of the perceptions of partner support among women with breast cancer, and are used with their permission. This was in order to replicate their study and to expand it in order to examine both men and women suffering with the same illness. Table A presents a summary of the main variables examined.
TABLE A: Summary of key measures (Patient Questionnaire)

<table>
<thead>
<tr>
<th>Type of Variable</th>
<th>Section number</th>
<th>Question numbers</th>
<th>Description</th>
<th>Time of administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>1</td>
<td>1 - 16</td>
<td>Demographic information</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>17 - 18</td>
<td>Personal history of stress</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>19</td>
<td>Most important source of support</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>20</td>
<td>Time since diagnosis + recent treatment (e.g. surgery, etc.)</td>
<td>✓</td>
</tr>
<tr>
<td>Communication</td>
<td>2</td>
<td>1 - 9</td>
<td>Expression of concerns &amp; feelings, helpfulness of disclosure, effectiveness, holding back</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>10</td>
<td>Barrett-Lennard Relationship Inventory (empathy scale)</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>11</td>
<td>Qualitative view of partner</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>12, 14 - 16</td>
<td>Perception of partner: stress level, supportiveness, criticalness, withdrawal</td>
<td>✓</td>
</tr>
<tr>
<td>Relationship</td>
<td>2</td>
<td>13</td>
<td>Relationship change</td>
<td>✓</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>2</td>
<td>17</td>
<td>Relationship happiness</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>18</td>
<td>Dyadic Adjustment scale</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>1 - 4</td>
<td>Significant Others Scale</td>
<td>✓</td>
</tr>
<tr>
<td>Psychological</td>
<td>3</td>
<td>1 - 29</td>
<td>Symptom Check List - 90 (SCL-90) (Anxiety, Depression, Hostility subscales)</td>
<td>✓</td>
</tr>
<tr>
<td>distress</td>
<td>5</td>
<td>1 - 10</td>
<td>Rosenberg Self-Esteem Scale</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td></td>
<td>Hospital Anxiety and Depression Scale (HAD)</td>
<td>✓</td>
</tr>
</tbody>
</table>

2.4.1 PATIENT QUESTIONNAIRE

The patient questionnaire (Appendix D1, page 227) was divided into six sections. It was estimated that the whole questionnaire (nearly 100 questions) could be completed within 40 minutes.

Section 1 included standard demographic questions (questions 1-16), a number of questions assessing personal history variables (question 17), and a question about concurrent stresses (question 18). The only items in the first questionnaire (Time-1) omitted from the second (Time-2) were these basic demographic and distant personal history questions (see Table A). Question 19
assessed the patient's most important source of support since they learned they had cancer and, finally, question 20 assessed time since diagnosis and recent treatment.

Section 2 was largely drawn from Pistrang and Barker's research protocol (personal communication). Questions assessing the extent of subjects' concerns and worries preceded questions which assessed the extent to which the subject had talked about these concerns or particular feelings to their partner (1-4). Questions 5 and 6 assessed how helpful the subject had found talking to their partner about these concerns or feelings along six-point scales. Question 7 assessed the adequacy of the extent of communication between subject and partner though items (a) and (c) were subsequently excluded because their implications for communication were ambiguous. Questions 8 and 9 were concerned with whether and why people may have held back from talking about their concerns or feelings. Question 10 measured empathy and was a ten-item subset from the revised Barrett-Lennard Relationship Inventory (Barrett-Lennard, 1978) with a reported coefficient alpha (i.e. internal consistency) of 0.83. The rest of Section 1 assessed the quality of the patient-partner relationship, both since the diagnosis of the cancer (questions 11 to 16: perceptions of how supportive, critical and withdrawn the partner had been) and more generally as measured by six items from the Dyadic Adjustment Scale (Spanier, 1976) (questions 18).

Section 3 (Problems and Complaints) included three subscales from the Symptom Check List (SCL-90) Derogatis, 1977). The subscales were Anxiety (10 items), Depression (13 items) and Hostility (6 items). Subjects responded according to a 5-point scale ranging from "not at all" to "extremely".

Section 4 (Your Relationship) was taken from the Significant Others Scale (SOS) (Power, Champion and Aris, 1988) which measures different functional aspects of perceived social support. This scale (which was not used by Pistrang and Barker) measures actual vs. ideal levels of support along four dimensions.
The scale was simplified to measure only perceived support from the subject’s partner.

Section 5 (Views about Yourself) was the widely-used ten-item Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1965). Finally, Section 6 comprised the Hospital Anxiety and Depression (HAD) Scale (Zigmond and Snaith, 1983) which has been widely used with cancer patients and contains 7-item subscales for both anxiety and depression.

2.4.2 PARTNER QUESTIONNAIRE
The partner questionnaire (Appendix D2, page 228) comprised a subset of questions from the patient questionnaire, and was estimated to take approximately 20 minutes to complete. Sections 1, 3, 4, 5, and 6 were virtually identical and excluded only items pertaining to the patient’s treatment. Section 2 was shortened to include only questions about the subject’s relationship with his or her partner.

2.4.3 THE INITIAL VIDEO FEEDBACK QUESTIONNAIRE
The initial video feedback questionnaire (Appendix D3, page 249) was primarily designed to help subjects personalise, internalise and remember the information they had seen on the video, as well as to consider possible barriers to following its advice (along the lines of the Health Belief Model), in the hope that this would enhance the effect of the intervention. Questions concerned the video’s importance, relevance and potential helpfulness as well as potential obstacles or barriers to enacting the advice in the video.

2.4.4 THE FOLLOW-UP VIDEO QUESTIONNAIRE
The follow-up video questionnaire (Appendix D4, page 249) was designed to obtain quantitative and qualitative information about the video at the end of the study. It was thus a retrospective self-report measure of unknown reliability, which asked subjects to consider to what extent the video had changed their behaviour and that of their partner.
2.5 Procedure

2.5.1 ETHICS
Ethical approval for the study was sought and obtained from four hospital Research Ethics Committees (Appendix B, page 207): United Bristol Healthcare NHS Trust, East Somerset NHS Trust, West Somerset (Taunton and Somerset Hospital), and Royal United Hospital Bath NHS Trust. The main ethical questions, peculiar to this research project, which were likely examined by the Ethics Committees were whether or not the questionnaires or intervention video were potentially damaging to participants, and whether those taking part in the video were compromised in any way in spite of their informed consent. For the purposes of obscuring the central purpose of the study from subjects, the research project was preliminarily entitled “An Evaluation of Two Psychosocial Videos”.

2.5.2 IMPLEMENTATION
Eligible patients were approached about the study while attending their first outpatient appointment with their oncologist to discuss their impending treatment (chemotherapy or radiotherapy). Their oncologist was instructed to ask the patient whether they felt that they and their partner might be prepared to receive more information about a study looking at “how couples cope when one of them has cancer”. Although no further information was given, it was explained that the couple might be asked to watch a video and the couple’s access to a video player was thus established. The name, sex and date or birth of all eligible patients approached was then passed onto the author by clinic staff with an indication whether or not the patient had agreed to receive further information.

Patients who had agreed to be contacted were then sent a letter (Appendix C, page 216), addressed to the patient and their partner, inviting them to
participate in the study. Enclosed with the letter was a detailed Consent Form (Appendix C, page 218) and a stamped addressed envelope for its return to the author.

Both members of consenting couples were then sent different questionnaires according to whether they were the patient or the partner (Appendix D1 & D2). These were contained in separate but unsealed stamped addressed envelopes, clearly marked with either the word 'Patient' or 'Partner' on the outside. A cover letter (Appendix C, page 249) gave instructions that the partners should complete the questionnaires separately, without consulting one another, before returning them to the author.

Once both questionnaires had been received, couples were consecutively assigned to the video or control group. This method of consecutive allocation was considered an adequate randomisation strategy in that it could not conceivably lead to any selection bias. There were four groups into which the couple could be assigned: female-patient intervention group, female-patient control group, male-patient intervention group, and male-patient control group.

Following randomisation, couples in the control group were sent a letter (Appendix C, page 223) explaining that they had been randomly assigned to the no-video (control) group, but reiterating that their continued participation was still vital to the research project. Couples in the intervention group were sent a copy of the video intervention, two copies of a short Initial Video Questionnaire (Facing it Together - Appendix D3, page 249) which, again, were concealed in separate clearly marked stamped addressed envelopes, two copies of a leaflet also entitled "Facing it Together" (Appendix E, page 250), and a cover letter asking the couple to watch the video together but without others present (Appendix C, page 222). The leaflet was designed to reiterate the prescriptive advice on the video and to act as an accessible prompt should the subject wish to refresh his or her memory.
Finally, three months after receipt of the first questionnaires, all couples were sent Time-2 questionnaires which were almost identical to those they had completed before. Again, these were concealed in marked stamped addressed envelopes, along with a cover letter (Appendix C, page 224) of instruction. Couples in the intervention group were also sent the Follow-up Video Questionnaire (Appendix D4, page 249) along with their main questionnaires. As soon as all these last questionnaires were received, the couple were sent a letter thanking them for their participation (Appendix C, page 225).

2.6 Statistical Analysis

There are essentially four explanatory perspectives from which the dataset can be viewed: patient/partner X male/female X intervention/control X Time-1/Time-2. This represents sixteen potential groupings of the data. In view of this complexity and the number of variables involved, the chances of a false positive result (Type 1 error) will be high if each variable is analysed from the perspective of all these various groupings. Clearly, a multivariate parametric approach is the preferred option when considering multiple outcome variables and explanatory factors.

However, all the variables in the current study (with the obvious exception of age) are binary, ordinal or categorical rather than continuous. Such data only allow subjects to be ranked in relation to one another; no assumptions can be made about the magnitude of the difference between any two scale points. Thus, particularly in view of the relatively small sample size, these kind of data require non-parametric statistical methods (Powell, 1996) which do not assume a normal distribution. Although non-parametric statistics are less powerful, their very conservativeness has advantages when so many variables are to be examined.
Hypotheses pertaining to gender differences were predominantly tested by cross-sectional examination of participants at Time-1. Hypotheses relating to the effect of the video intervention were tested by first calculating change scores for each participant from Time-1 to Time-2, and then comparing change scores between the two groups.

Data were manipulated and analysed using SPSS Windows (version 8), Excel and Access computer programs. Note that with respect to the Mann-Whitney U Test, SPSS for Windows does not calculate a significance level for the U test but instead gives the related Z statistic and its significance level. The Z statistic corrects for scores receiving the same rank. This means that if Z is not significant, nor will U. Hence, for the following analyses, using the Mann-Whitney test, the value of Z and not U will be reported.
3. RESULTS

The results will be presented in seven sections:

3.1 DEMOGRAPHIC FEATURES OF THE SAMPLE
3.2 COMPARISON OF THE VIDEO AND CONTROL GROUPS AT TIME-1
3.3 COMPARISON OF CHANGE SCORES BETWEEN THE VIDEO AND CONTROL GROUPS FROM TIME-1 TO TIME-2
3.4 RELATIONSHIP BETWEEN COMMUNICATION AND RELATIONSHIP VARIABLES AND PSYCHOLOGICAL DISTRESS
3.5 GENDER DIFFERENCES
3.6 INITIAL VIDEO FEEDBACK QUESTIONNAIRE
3.7 FOLLOW-UP VIDEO FEEDBACK QUESTIONNAIRE

3.1 Demographic Features of the Sample

3.1.1 PARTICIPANTS, REFUSALS AND DROP-OUTS

In total, 80 eligible couples (of which 41 contained male patients) were approached over a ten month period. Of these, 9 male-patient couples and 5 female patient couples refused to receive further information about the study. A further 6 male-patient and 5 female-patient couples declined to participate after obtaining consent information about the study and of those who consented to the study, 3 male-patient and 6 female-patient couples subsequently failed to return their pre-test questionnaires. This left an initial sample of 46 couples (70% of those receiving the consent information) who were randomly allocated to the Video (n=23) intervention and Control (n=23) groups. Patients who either refused or dropped out of the study were not significantly different in either age or sex from patients who participated.

At Time-2, 3 months after randomisation, four couples (3 female-patient and 1 male-patient) failed to respond to the questionnaires and the reminders sent to them. Of these, three were in the control group and one was in the video
group. There were no differences between these couples and the rest of the sample in age or on any psychological variable except SCL-90 Depression on which they scored significantly lower (Mann-Whitney, z=2.10, p=0.036).

### 3.1.2 DEMOGRAPHIC AND PERSONAL HISTORY VARIABLES

The mean age of the patients and partners (n=92) was 58.4 years with a preponderance of patient subjects in their sixties (see Figure 1)

**FIGURE 1: Age Distribution of patients in the video and control groups**

There were no statistically significant differences between the video and control groups on demographic variables (see Table 1), with two exceptions: significantly more control group partners than video group partners reported that they had previously coped with a family member with cancer; and control group subjects left school significantly later than video group subjects.
### TABLE 1: Demographic Characteristics of Video and Control Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video (n=23)</th>
<th>Control (n=23)</th>
<th>Test statistic</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of patient</td>
<td>Male (n)</td>
<td>Female (n)</td>
<td>Test statistic</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>11</td>
<td>Chi²=0.087</td>
<td>0.770</td>
</tr>
<tr>
<td>Patients' age mean (sd)</td>
<td>58.91 (11.35)</td>
<td>58.04 (11.73)</td>
<td>t=0.255</td>
<td>0.800</td>
</tr>
<tr>
<td>Partners' age mean (sd)</td>
<td>60.52 (10.94)</td>
<td>56.04 (12.72)</td>
<td>t=1.28</td>
<td>0.207</td>
</tr>
<tr>
<td>Length of relationship mean (sd)</td>
<td>33.24 (14.30)</td>
<td>29.09 (16.26)</td>
<td>t=1.28</td>
<td>0.201</td>
</tr>
<tr>
<td>Number of children mean (sd)</td>
<td>2.04 (0.98)</td>
<td>1.95 (0.94)</td>
<td>t=0.443</td>
<td>0.659</td>
</tr>
<tr>
<td>Age of youngest child mean (sd)</td>
<td>28.55 (11.81)</td>
<td>27.20 (10.87)</td>
<td>t=0.548</td>
<td>0.585</td>
</tr>
<tr>
<td>Patients' school leaving age mean (sd)</td>
<td>15.48 (1.62)</td>
<td>17.54 (3.74)</td>
<td>t=2.43</td>
<td>0.020</td>
</tr>
<tr>
<td>Partners' school leaving age mean (sd)</td>
<td>15.40 (1.63)</td>
<td>18.04 (4.73)</td>
<td>t=2.37</td>
<td>0.020</td>
</tr>
<tr>
<td>Weeks since diagnosis mean (sd)</td>
<td>11.35 (5.48)</td>
<td>11.32 (8.67)</td>
<td>t=0.014</td>
<td>0.989</td>
</tr>
<tr>
<td>Surgery over past 2 months n (%)</td>
<td>8 (35)</td>
<td>14 (61)</td>
<td>Chi²=3.13</td>
<td>0.077</td>
</tr>
<tr>
<td>Chemotherapy over past 2 months n (%)</td>
<td>16 (70)</td>
<td>10 (43)</td>
<td>Chi²=3.18</td>
<td>0.074</td>
</tr>
<tr>
<td>Radiotherapy over past 2 months n (%)</td>
<td>5 (22)</td>
<td>6 (26)</td>
<td>Chi²=0.12</td>
<td>0.730</td>
</tr>
<tr>
<td>Patients' family history of cancer n (%)</td>
<td>7 (30)</td>
<td>10 (43)</td>
<td>Chi²=1.08</td>
<td>0.299</td>
</tr>
<tr>
<td>Partners' family history of cancer n (%)</td>
<td>2 (9)</td>
<td>9 (39)</td>
<td>Chi²=5.85</td>
<td>0.016</td>
</tr>
</tbody>
</table>

No direct measure of cancer symptomatology or functional performance was made. One recruitment criterion was an assessment by the patient's doctor that the patient would survive at least one year. No patients died during the course of the study. Time-2 measures of cancer treatment over the prior three months (i.e. the course of the study) indicated no difference between the groups on surgery (Chi-square=3.55, p=0.059), radiotherapy (Chi-square=2.47, p=0.116), or chemotherapy (Chi-square=2.444, p=0.118).

### 3.2 Comparison of the Video and Control Groups at Time-1

#### 3.2.1 COMPARISON OF PATIENTS IN THE VIDEO AND CONTROL GROUPS AT TIME-1

Patients in the video and control groups were compared as to their sources of support, communication, relationship, and psychological variables at Time-1 to investigate whether randomisation had been effective. Table 2 indicates that...
although the two groups did not differ in the source of the main support, patients in the control group rated their partners as significantly more empathic than video group patients \( p=0.047 \). They also reported a tendency to find talking to their partners as more effective \( p=0.058 \) than those in the video group. Whilst there were no differences between the groups in terms of relationship satisfaction, there were differences on psychological variables. Video group patients had higher scores on SCL-Depression \( p=0.040 \), SCL-Hostility \( p=0.016 \) and HAD-Depression \( p=0.018 \), representing a failure of randomisation.

**TABLE 2:** Comparison of Patient Subjects in the Video and Control Groups on Key Outcome Variables at Time-1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video (n=23)</th>
<th>Control (n=23)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner as the most important source of support ( n(%) )</td>
<td>18 (78)</td>
<td>19 (83)</td>
<td>1.20</td>
<td>0.548</td>
</tr>
<tr>
<td>Male as most important source of support ( n(%) )</td>
<td>6 (26)</td>
<td>10 (43)</td>
<td>1.06</td>
<td>0.303</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Talked about concerns</td>
<td>2.11 (1.04)</td>
<td>2.16 (1.16)</td>
<td>0.212</td>
<td>0.832</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>2.06 (1.18)</td>
<td>2.55 (1.26)</td>
<td>1.467</td>
<td>0.142</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>2.05 (1.80)</td>
<td>2.48 (1.17)</td>
<td>0.784</td>
<td>0.433</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>11.55 (5.05)</td>
<td>14.41 (5.42)</td>
<td>1.896</td>
<td>0.058</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>0.82 (0.91)</td>
<td>0.64 (0.73)</td>
<td>-0.561</td>
<td>0.575</td>
</tr>
<tr>
<td>(10) Empathy of partner</td>
<td>11.23 (10.78)</td>
<td>16.64 (10.60)</td>
<td>1.989</td>
<td>0.047</td>
</tr>
<tr>
<td>(14) Supportiveness of partner</td>
<td>4.61 (5.61)</td>
<td>3.82 (5.50)</td>
<td>1.275</td>
<td>0.202</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>0.50 (0.86)</td>
<td>0.41 (0.67)</td>
<td>-0.129</td>
<td>0.898</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>0.18 (0.85)</td>
<td>0.18 (0.39)</td>
<td>1.322</td>
<td>0.186</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13) Relationship change</td>
<td>3.65 (0.88)</td>
<td>3.45 (0.74)</td>
<td>-0.695</td>
<td>0.487</td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>0.76 (1.04)</td>
<td>1.30 (1.22)</td>
<td>1.574</td>
<td>0.116</td>
</tr>
<tr>
<td>(18) Dyadic Adjustment Scale</td>
<td>0.67 (1.91)</td>
<td>0.68 (3.08)</td>
<td>0.568</td>
<td>0.570</td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>-2.1 (3.24)</td>
<td>-1.1 (2.39)</td>
<td>-1.260</td>
<td>0.208</td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>8.14 (4.49)</td>
<td>9.14 (5.29)</td>
<td>0.796</td>
<td>0.426</td>
</tr>
<tr>
<td>SCL-Anxiety</td>
<td>6.55 (5.88)</td>
<td>5.23 (5.84)</td>
<td>-1.390</td>
<td>0.164</td>
</tr>
<tr>
<td>SCL-Depression</td>
<td>10.95 (6.13)</td>
<td>7.50 (6.12)</td>
<td>-2.059</td>
<td>0.040</td>
</tr>
<tr>
<td>SCL-Hostility</td>
<td>2.05 (2.19)</td>
<td>0.82 (1.44)</td>
<td>-2.407</td>
<td>0.016</td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>5.91 (5.13)</td>
<td>4.00 (2.99)</td>
<td>-1.370</td>
<td>0.171</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>4.00 (3.01)</td>
<td>1.95 (1.73)</td>
<td>-2.37</td>
<td>0.018</td>
</tr>
</tbody>
</table>
3.2.2 COMPARISON OF PARTNERS IN THE VIDEO AND CONTROL GROUPS AT TIME-1

As can be seen from Table 3, partners in the control group were significantly more likely to have chosen a man as their main source of support since the diagnosis of their partner’s cancer (p=0.011). The two groups were otherwise similar except for higher levels of partner criticism in the video group (p=0.033) and a non-significant tendency for control group partners to have higher self-esteem scores (p=0.058).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video (n=23)</th>
<th>Control (n=23)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner as the most important source of support n (%)</td>
<td>9 (39)</td>
<td>12 (52)</td>
<td>1.629</td>
<td>0.443</td>
</tr>
<tr>
<td>Male as most important source of support n (%)</td>
<td>2 (9)</td>
<td>10 (43)</td>
<td>6.453</td>
<td>0.011</td>
</tr>
</tbody>
</table>

**TABLE 3: Comparison of Partner Subjects in the Video and Control Groups on Key Outcome Variables at Time-1**
3.2.3 DIFFERENCES BETWEEN PATIENTS AND PARTNERS ON KEY VARIABLES

There were only two significant differences at Time-1 between patients and partners. Patients' assessments of their partners' supportiveness were significantly higher than partners' assessments of the patients' supportiveness (Wilcoxon Signed Ranks test, z = 3.51, p < 0.001) which is perhaps not surprising given their relative situations. More interesting was the finding that partners perceived their spouses to have withdrawn (question 16) significantly more than patients perceived their partners to have withdrawn (Wilcoxon Signed Ranks test, z = 2.56, p = 0.010) though there was no difference in perceived criticism between patients and partners at Time-1 (Wilcoxon Signed Ranks test, z=0.420, p=0.674).

3.3 Comparison of Change Scores in the Video and Control Groups

Change Scores

The means and standard deviations of the experimental variables at Time-1 for both the video and control group have been presented in Tables 2 & 3. Change scores were calculated for each subject for each variable by subtracting the Time-2 score from the Time-1 score. The video and control groups were then compared according to the resulting change scores (Note: Tables 4 & 7 exclude data from the four couples who had dropped out of the study by Time-2).

The raw means and standard deviations for both patients and partners in the two groups are presented in Tables 5,6, 8 and 9, which include within-group comparisons from Time-1 to Time-2 for all subjects.
3.3.1 EFFECT OF THE VIDEO ON PATIENT SUBJECTS

The video appeared to have had limited impact on patients' perception of their most important source of support (Table 4) with one more subject in the video group and two less subjects in the control group designating their partner as their most important source of support. Among the outcome variables only three change scores were significantly different between the groups. The perception of the partner's supportiveness fell in the control group while it remained the same in the video group (p=0.029). The perceived happiness of the relationship (question 17) improved for subjects in the video group while it declined in the control group (p=0.022).

There were no significant differences between the groups in change scores on any measure of psychopathology except for the depression scale of the HAD on which patient control subjects became more depressed while video subjects became less depressed, a significant group difference (p=0.009). However, it must be borne in mind that at Time-1 the video group had significantly higher scores on both HAD-Depression and SCL-Depression and thus it is unclear whether this difference in the change scores between the groups reflects regression towards the mean or a genuine effect of the video. The change in HAD-Depression was not supported by similar changes in SCL-Depression.
### TABLE 4: Comparison of Change Scores among Video and Control Patient Subjects

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video T2-T1 (n=22)</th>
<th>Control T2-T1 (n=20)</th>
<th>Chi-square (df=2)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner as the most important source of support</td>
<td>+1</td>
<td>-2</td>
<td>2.270</td>
<td>0.321</td>
</tr>
<tr>
<td>Male as most important source of support</td>
<td>+3</td>
<td>-2</td>
<td>4.943</td>
<td>0.084</td>
</tr>
<tr>
<td>Variable</td>
<td>Video Group (n=22)</td>
<td>Control Group n=20</td>
<td>Change Mann-Whitney z =</td>
<td>Change p-value</td>
</tr>
<tr>
<td>----------</td>
<td>---------------------</td>
<td>---------------------</td>
<td>-------------------</td>
<td>---------</td>
</tr>
<tr>
<td>(3) Talked about concerns</td>
<td>2.13 (1.04)</td>
<td>2.10 (1.17)</td>
<td>0.05 (1.07)</td>
<td>0.683 (0.495)</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>2.05 (1.18)</td>
<td>2.42 (1.35)</td>
<td>-0.129 (0.81)</td>
<td>-1.408 (0.159)</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>1.95 (1.78)</td>
<td>2.35 (1.22)</td>
<td>-0.35 (1.81)</td>
<td>0.621 (0.535)</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>10.58 (5.87)</td>
<td>13.05 (6.21)</td>
<td>0.85 (4.06)</td>
<td>0.127 (0.899)</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>0.68 (0.84)</td>
<td>0.80 (0.77)</td>
<td>0.10 (0.45)</td>
<td>1.251 (0.211)</td>
</tr>
<tr>
<td>(10) Empathy of partner</td>
<td>11.55 (10.53)</td>
<td>15.30 (10.56)</td>
<td>0.05 (5.37)</td>
<td>-1.213 (0.225)</td>
</tr>
<tr>
<td>(14) Supportiveness of partner</td>
<td>3.50 (0.91)</td>
<td>3.70 (0.66)</td>
<td>-0.35 (0.59)</td>
<td>-2.189 (0.029)</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>0.50 (0.86)</td>
<td>0.45 (0.69)</td>
<td>-0.25 (0.79)</td>
<td>-0.241 (0.809)</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>0.18 (0.85)</td>
<td>0.20 (0.41)</td>
<td>0.00 (0.46)</td>
<td>-1.249 (0.212)</td>
</tr>
<tr>
<td>(13) Relationship change</td>
<td>3.68 (0.89)</td>
<td>3.50 (0.76)</td>
<td>-0.15 (0.37)</td>
<td>-0.377 (0.706)</td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>0.73 (1.03)</td>
<td>1.05 (1.28)</td>
<td>-0.40 (1.09)</td>
<td>-2.286 (0.022)</td>
</tr>
<tr>
<td>(18) Dyadic Adjustment Scale</td>
<td>0.68 (1.86)</td>
<td>0.50 (3.24)</td>
<td>0.00 (1.62)</td>
<td>0.079 (0.937)</td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>-1.73 (2.80)</td>
<td>-1.35 (2.46)</td>
<td>-0.55 (2.42)</td>
<td>-0.581 (0.561)</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>8.00 (4.44)</td>
<td>8.47 (6.12)</td>
<td>-0.37 (4.56)</td>
<td>-0.710 (0.478)</td>
</tr>
<tr>
<td>SCL-Anxiety</td>
<td>6.45 (4.91)</td>
<td>5.00 (5.82)</td>
<td>-0.20 (6.77)</td>
<td>0.038 (0.970)</td>
</tr>
<tr>
<td>SCL-Depression</td>
<td>10.55 (6.22)</td>
<td>7.50 (6.39)</td>
<td>3.10 (9.55)</td>
<td>0.088 (0.930)</td>
</tr>
<tr>
<td>SCL-Hostility</td>
<td>2.05 (2.19)</td>
<td>0.90 (1.48)</td>
<td>0.75 (2.08)</td>
<td>0.917 (0.359)</td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>5.82 (4.20)</td>
<td>4.05 (2.93)</td>
<td>0.10 (3.95)</td>
<td>0.943 (0.346)</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>4.00 (3.01)</td>
<td>2.00 (1.75)</td>
<td>1.50 (3.87)</td>
<td>2.597 (0.009)</td>
</tr>
</tbody>
</table>
Tables 5 and 6 indicate that while there were no significant differences in any of the variables from Time-1 to Time-2 among video group patients, there was a significant decline in the perception of partner supportiveness among control group patients (Wilcoxon z=2.33, p=0.020) and a significant increase in both SCL-Hostility (Wilcoxon z=2.33, p=0.020) and HAD-Depression (Wilcoxon z=2.520, p=0.012). This suggests that the between group changes in supportiveness and HAD-depression were more the result of a decline among control patients on these variables from Time-1 to Time-2, rather than an improvement among video group patients.

### TABLE 5: Comparison of Video Patients at Time-1 and Time-2

<table>
<thead>
<tr>
<th>Source of support</th>
<th>Variable</th>
<th>TIME-1 (n=23)</th>
<th>TIME-2 (n=22)</th>
<th>McNemar</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partner as the most important source of support n (%)</td>
<td>18 (78)</td>
<td>19 (86)</td>
<td>—</td>
<td>1.000</td>
</tr>
<tr>
<td></td>
<td>Male as most important source of support n (%)</td>
<td>6 (26)</td>
<td>9 (41)</td>
<td>—</td>
<td>0.250</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME-1</th>
<th>TIME-2</th>
<th>Wilcoxon z</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>s.d.</td>
<td>Mean</td>
<td>s.d.</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>-------------</td>
<td>---------</td>
</tr>
<tr>
<td>(3) Talked about concerns</td>
<td>2.11</td>
<td>1.04</td>
<td>1.88</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>2.06</td>
<td>1.18</td>
<td>2.21</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>2.05</td>
<td>1.80</td>
<td>0.86</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>11.55</td>
<td>5.05</td>
<td>12.00</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>0.82</td>
<td>0.91</td>
<td>0.76</td>
</tr>
<tr>
<td>(10) Empathy of partner</td>
<td>11.23</td>
<td>10.78</td>
<td>13.55</td>
</tr>
<tr>
<td>(14) Supportiveness of partner</td>
<td>4.61</td>
<td>5.61</td>
<td>3.59</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>0.50</td>
<td>0.86</td>
<td>0.36</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>0.18</td>
<td>0.85</td>
<td>0.45</td>
</tr>
<tr>
<td>(13) Relationship change</td>
<td>3.65</td>
<td>0.88</td>
<td>3.59</td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>0.76</td>
<td>1.04</td>
<td>0.95</td>
</tr>
<tr>
<td>(18) Dyadic Adjustment Scale</td>
<td>0.67</td>
<td>1.91</td>
<td>0.41</td>
</tr>
</tbody>
</table>

| Significant Others Scale | -2.1 | 3.24 | -1.95 | 3.28 | 0.604 | 0.546 |

**Psychological**

| Self-Esteem | 8.14 | 4.49 | 8.09 | 4.55 | 0.263 | 0.793 |
| SCL-Anxiety | 6.55 | 4.86 | 5.50 | 4.13 | 0.963 | 0.336 |
| SCL-Depression | 10.95 | 6.13 | 13.09 | 8.22 | 1.684 | 0.092 |
| SCL-Hostility | 2.05 | 2.19 | 2.14 | 2.29 | 0.029 | 0.977 |
| HAD-Anxiety | 5.91 | 4.13 | 5.00 | 3.02 | 1.383 | 0.167 |
| HAD-Depression | 4.00 | 3.01 | 3.64 | 3.14 | 0.909 | 0.363 |
TABLE 6: Comparison of Control Patients at Time-1 and Time-2

<table>
<thead>
<tr>
<th>Variable</th>
<th>TIME-1 (n=23)</th>
<th>TIME-2 (n=20)</th>
<th>McNemar</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner as the most important source of support n (%)</td>
<td>19 (83)</td>
<td>17 (85)</td>
<td>—</td>
<td>0.500</td>
</tr>
<tr>
<td>Male as most important source of support n (%)</td>
<td>10 (43)</td>
<td>8 (40)</td>
<td>—</td>
<td>0.500</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Talked about concerns</td>
<td>2.16</td>
<td>1.16</td>
<td>2.15</td>
<td>1.16</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>2.55</td>
<td>1.26</td>
<td>2.39</td>
<td>1.08</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>2.48</td>
<td>1.17</td>
<td>2.00</td>
<td>1.59</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>14.41</td>
<td>5.42</td>
<td>13.90</td>
<td>5.90</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>0.64</td>
<td>0.73</td>
<td>0.70</td>
<td>0.73</td>
</tr>
<tr>
<td>(10) Empathy of partner</td>
<td>16.64</td>
<td>10.60</td>
<td>15.00</td>
<td>10.73</td>
</tr>
<tr>
<td>(14) Supportiveness of partner</td>
<td>3.82</td>
<td>0.50</td>
<td>3.35</td>
<td>0.88</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>0.41</td>
<td>0.67</td>
<td>0.20</td>
<td>0.52</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>0.18</td>
<td>0.39</td>
<td>0.20</td>
<td>0.62</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13) Relationship change</td>
<td>3.45</td>
<td>0.74</td>
<td>3.35</td>
<td>0.74</td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>1.30</td>
<td>1.22</td>
<td>0.65</td>
<td>1.09</td>
</tr>
<tr>
<td>(18) Dyadic Adjustment Scale</td>
<td>0.68</td>
<td>3.08</td>
<td>0.50</td>
<td>3.32</td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>-1.1</td>
<td>2.39</td>
<td>-1.90</td>
<td>4.02</td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>9.14</td>
<td>5.29</td>
<td>8.10</td>
<td>4.56</td>
</tr>
<tr>
<td>SCL-Anxiety</td>
<td>5.23</td>
<td>5.84</td>
<td>4.80</td>
<td>6.77</td>
</tr>
<tr>
<td>SCL-Depression</td>
<td>7.50</td>
<td>6.12</td>
<td>10.60</td>
<td>9.55</td>
</tr>
<tr>
<td>SCL-Hostility</td>
<td>0.82</td>
<td>1.44</td>
<td>1.65</td>
<td>2.08</td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>4.00</td>
<td>2.99</td>
<td>4.15</td>
<td>3.95</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>1.95</td>
<td>1.73</td>
<td>3.50</td>
<td>3.87</td>
</tr>
</tbody>
</table>

3.3.2 EFFECT OF THE VIDEO ON PARTNER SUBJECTS

There were no statistically significant differences between the video and control groups in terms of the partners' change scores from Time-1 to Time-2 (Table 7) though four subjects in the video group changed their choice of their most important source of support to their partners (i.e. the patient). However, paradoxically, there was also a significant decline in perceived partner (i.e. patient) supportiveness from Time-1 to Time-2 (Wilcoxon z=2.33, p=0.020;
Table 8) among the video group partners. In addition, among the control group partners there was a reduction in HAD-Anxiety from Time-1 to Time-2 (Wilcoxon z=2.012, p=0.044; Table 9).

**TABLE 7: Comparison of Change Scores among Video and Control Partner Subjects**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video Group (n=22)</th>
<th>Control Group (n=20)</th>
<th>Chi-square (d.f.=2)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner as the most important source of support</td>
<td>+4 (n=22)</td>
<td>0 (n=20)</td>
<td>2.806</td>
<td>0.246</td>
</tr>
<tr>
<td>Male as most important source of support</td>
<td>+5 (n=22)</td>
<td>0 (n=20)</td>
<td>3.608</td>
<td>0.165</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Video Group (n=22) mean (sd)</th>
<th>Control Group (n=20) mean (sd)</th>
<th>Change T1 T2</th>
<th>Mann-Whitney z=</th>
<th>Change p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Supportiveness of partner</td>
<td>3.23 (0.69)</td>
<td>2.91 (0.75)</td>
<td>-0.32 (1.14)</td>
<td>2.85 (0.83)</td>
<td>0.10 (0.97)</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>0.73 (0.88)</td>
<td>0.86 (0.99)</td>
<td>0.14 (0.77)</td>
<td>0.35 (0.75)</td>
<td>0.55 (0.83)</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>0.36 (0.73)</td>
<td>0.50 (0.67)</td>
<td>0.136 (0.94)</td>
<td>0.65 (0.88)</td>
<td>0.55 (0.60)</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13) Relationship change</td>
<td>3.45 (0.74)</td>
<td>3.59 (0.80)</td>
<td>0.136 (0.56)</td>
<td>3.55 (0.89)</td>
<td>3.40 (0.82)</td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>1.05 (1.36)</td>
<td>0.86 (1.04)</td>
<td>-0.182 (1.00)</td>
<td>1.15 (1.14)</td>
<td>0.90 (0.85)</td>
</tr>
<tr>
<td>(18) Dyadic Adjustment Scale</td>
<td>0.77 (2.83)</td>
<td>1.00 (2.47)</td>
<td>0.23 (1.19)</td>
<td>0.30 (2.03)</td>
<td>0.60 (2.64)</td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>-1.10 (2.62)</td>
<td>-1.62 (2.40)</td>
<td>-0.52 (2.16)</td>
<td>-2.10 (2.71)</td>
<td>-1.90 (2.90)</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>5.14 (4.57)</td>
<td>5.95 (4.66)</td>
<td>0.82 (2.52)</td>
<td>7.10 (4.69)</td>
<td>8.05 (4.57)</td>
</tr>
<tr>
<td>SCL-Anxiety</td>
<td>7.09 (7.20)</td>
<td>6.27 (6.47)</td>
<td>-0.82 (5.09)</td>
<td>6.65 (4.08)</td>
<td>5.20 (4.29)</td>
</tr>
<tr>
<td>SCL-Depression</td>
<td>12.64 (9.05)</td>
<td>11.41 (9.44)</td>
<td>-1.23 (6.67)</td>
<td>12.45 (6.77)</td>
<td>9.15 (8.31)</td>
</tr>
<tr>
<td>SCL-Hostility</td>
<td>2.05 (2.36)</td>
<td>2.32 (2.50)</td>
<td>0.27 (2.47)</td>
<td>1.70 (1.63)</td>
<td>1.90 (2.86)</td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>6.86 (3.87)</td>
<td>6.82 (4.54)</td>
<td>-0.04 (3.15)</td>
<td>6.50 (3.27)</td>
<td>5.05 (2.91)</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>3.73 (2.90)</td>
<td>3.91 (3.79)</td>
<td>0.18 (2.50)</td>
<td>3.50 (1.91)</td>
<td>3.15 (2.62)</td>
</tr>
</tbody>
</table>

**Psychological**
TABLE 8: Comparison of Video Partners at Time-1 and Time-2

<table>
<thead>
<tr>
<th>Source of support</th>
<th>Variable</th>
<th>TIME-1 (n=23)</th>
<th>TIME-2 (n=22)</th>
<th>McNemar</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partner as the most important source of support n (%)</td>
<td>9 (39)</td>
<td>13 (59)</td>
<td>—</td>
<td>0.250</td>
</tr>
<tr>
<td></td>
<td>Male as most important source of support n (%)</td>
<td>2 (9)</td>
<td>7 (32)</td>
<td>—</td>
<td>0.063</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME-1</th>
<th>TIME-2</th>
<th>Wilcoxon Z=</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>s.d.</td>
<td>Mean</td>
<td>s.d.</td>
</tr>
</tbody>
</table>

| Communication  | (14) Supportiveness of partner | 3.17 | 0.72 | 2.91 | 0.75 | 2.333 | 0.020 |
|                | (15) Partner criticism         | 0.74 | 0.86 | 0.96 | 0.99 | 0.832 | 0.405 |
|                | (16) Partner withdrawal        | 0.35 | 0.71 | 0.50 | 0.67 | 0.952 | 0.341 |
| Relationship   | (13) Relationship change       | 3.43 | 0.73 | 3.59 | 0.79 | 1.134 | 0.257 |
|                | (17) Happiness of relationship | 1.05 | 1.36 | 0.86 | 1.04 | 0.842 | 0.400 |
|                | (18) Dyadic Adjustment Scale   | 0.78 | 2.76 | 1.00 | 2.47 | 0.852 | 0.394 |
|                | Significant Others Scale       | -1.18| 2.59 | -1.50| 2.33 | 1.046 | 0.296 |
| Psychological  | Self-Esteem                     | 5.32 | 4.64 | 5.95 | 4.66 | 1.430 | 0.153 |
|                | SCL-Anxiety                     | 6.96 | 7.07 | 6.27 | 6.47 | 0.594 | 0.552 |
|                | SCL-Depression                  | 12.17| 9.12 | 11.41| 9.44 | 1.189 | 0.235 |
|                | SCL-Hostility                   | 2.0  | 2.32 | 2.32 | 2.50 | 0.416 | 0.677 |
|                | HAD-Anxiety                     | 6.74 | 3.63 | 6.82 | 4.54 | 0.000 | 1.000 |
|                | HAD-Depression                  | 3.61 | 2.89 | 3.91 | 3.79 | 0.242 | 0.809 |
### TABLE 9: Comparison of Control Partners at Time-1 and Time-2

<table>
<thead>
<tr>
<th>Variable</th>
<th>TIME-1 (n=23)</th>
<th>TIME-2 (n=20)</th>
<th>McNemar</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner as the most important source of support n (%)</td>
<td>12 (52)</td>
<td>12 (60)</td>
<td>—</td>
<td>1.000</td>
</tr>
<tr>
<td>Male as most important source of support n (%)</td>
<td>10 (43)</td>
<td>10 (50)</td>
<td>—</td>
<td>1.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>TIME-1</th>
<th>TIME-2</th>
<th>Wilcoxon z</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportiveness of partner</td>
<td>2.91</td>
<td>2.95</td>
<td>0.504</td>
<td>0.614</td>
</tr>
<tr>
<td>Partner criticism</td>
<td>0.30</td>
<td>0.58</td>
<td>1.265</td>
<td>0.206</td>
</tr>
<tr>
<td>Partner withdrawal</td>
<td>0.61</td>
<td>0.55</td>
<td>0.632</td>
<td>0.527</td>
</tr>
<tr>
<td>Relationship change</td>
<td>3.47</td>
<td>3.40</td>
<td>1.000</td>
<td>0.317</td>
</tr>
<tr>
<td>Happiness of relationship</td>
<td>1.00</td>
<td>0.90</td>
<td>1.155</td>
<td>0.248</td>
</tr>
<tr>
<td>Dyadic Adjustment Scale</td>
<td>0.35</td>
<td>0.60</td>
<td>0.566</td>
<td>0.571</td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>-1.96</td>
<td>-1.89</td>
<td>0.595</td>
<td>0.552</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>7.95</td>
<td>8.05</td>
<td>1.429</td>
<td>0.153</td>
</tr>
<tr>
<td>SCL-Anxiety</td>
<td>5.61</td>
<td>5.20</td>
<td>1.213</td>
<td>0.225</td>
</tr>
<tr>
<td>SCL-Depression</td>
<td>11.30</td>
<td>9.15</td>
<td>1.683</td>
<td>0.092</td>
</tr>
<tr>
<td>SCL-Hostility</td>
<td>1.57</td>
<td>1.90</td>
<td>0.360</td>
<td>0.719</td>
</tr>
<tr>
<td>HAD-Anxiety</td>
<td>6.17</td>
<td>5.05</td>
<td>2.012</td>
<td>0.044</td>
</tr>
<tr>
<td>HAD-Depression</td>
<td>3.30</td>
<td>3.15</td>
<td>0.888</td>
<td>0.375</td>
</tr>
</tbody>
</table>

### 3.4 Relationship between Communication Variables and Psychological distress

**Psychological distress**

A central question of this research was whether the quality of partner support experienced by people coping with the stress of cancer influences the development of psychological distress. While this cannot be conclusively answered using correlational analysis (which only indicate mutual associations between variables), the concurrent relationships at Time-1 and Time-2, and the predictive relationships from Time-1 to Time-2, between communication variables and psychological distress will be presented. In view of the fact that there were relatively few differences between the video and control groups, their
data will be combined in these analyses. Considering the large number of correlations which follow, caution should be exercised in their interpretation.

3.4.1 RELATIONSHIP BETWEEN PATIENT-ASSESSED COMMUNICATION VARIABLES AND PATIENT DISTRESS

Time-1

Table 10 presents correlations between communication variables and patient distress at Time-1. It can be seen that there were no statistically significant associations between communication and psychological variables at Time-1. The one exception was that self-esteem was positively associated with perceived partner empathy (p=0.009).

**TABLE 10: Correlation Matrix between Patient-assessed Communication and Psychological Variables at Time-1 (N=42)**

<table>
<thead>
<tr>
<th></th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) Talked about concerns</td>
<td>r = -0.126</td>
<td>p = 0.432</td>
<td>r = 0.201</td>
<td>p = 0.042</td>
<td>r = -0.059</td>
<td>p = 0.709</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>r = 0.135</td>
<td>p = 0.399</td>
<td>r = 0.071</td>
<td>p = 0.653</td>
<td>r = 0.175</td>
<td>p = 0.614</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>r = -0.087</td>
<td>p = 0.587</td>
<td>r = 0.194</td>
<td>p = 0.219</td>
<td>r = -0.005</td>
<td>p = 0.976</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>r = -0.233</td>
<td>p = 0.143</td>
<td>r = -0.031</td>
<td>p = 0.844</td>
<td>r = -0.133</td>
<td>p = 0.251</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>r = -0.054</td>
<td>p = 0.738</td>
<td>r = 0.050</td>
<td>p = 0.751</td>
<td>r = -0.256</td>
<td>p = 0.928</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Empathy</td>
<td>r = -0.402</td>
<td>p = 0.009</td>
<td>r = -0.105</td>
<td>p = 0.510</td>
<td>r = -0.207</td>
<td>p = 0.442</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Supportiveness</td>
<td>r = 0.148</td>
<td>p = 0.355</td>
<td>r = -0.138</td>
<td>p = 0.383</td>
<td>r = -0.238</td>
<td>p = 0.662</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>r = 0.083</td>
<td>p = 0.607</td>
<td>r = 0.213</td>
<td>p = 0.175</td>
<td>r = 0.245</td>
<td>p = 0.754</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>r = -0.120</td>
<td>p = 0.455</td>
<td>r = 0.246</td>
<td>p = 0.116</td>
<td>r = -0.017</td>
<td>p = 0.259</td>
</tr>
</tbody>
</table>

*Spearman's rho
At Time-2, there were a number of associations between patients’ perceptions of their partner’s communication behaviour and their own levels of psychological distress (Table 11). In particular, the more effective the patient found it to talk to their partner at Time-2, the more likely they were to have low scores on HAD-Anxiety and SCL-Depression and a higher score on self-esteem. The helpfulness of talking and the supportiveness of the partner were negatively associated with HAD-Anxiety while partner criticism was more strongly correlated with patients’ feelings of hostility. Finally partner withdrawal was associated with lower self-esteem.

**TABLE 11: Correlation Matrix between Patient-assessed Communication and Psychological Variables at Time-2 (N=42)**

<table>
<thead>
<tr>
<th></th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) Talked about concerns</td>
<td>r 0.035</td>
<td>p 0.828</td>
<td>S 0.024</td>
<td>D 0.042</td>
<td>H 0.122</td>
<td>A 0.326</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>r -0.777</td>
<td>p 0.633</td>
<td>S -0.036</td>
<td>D -0.122</td>
<td>H 0.063</td>
<td>A -0.301</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>r 0.044</td>
<td>p 0.784</td>
<td>S -0.128</td>
<td>D -0.167</td>
<td>H 0.010</td>
<td>A -0.365</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>r 0.319</td>
<td>p 0.042</td>
<td>S -0.274</td>
<td>D -0.338</td>
<td>H 0.048</td>
<td>A -0.396</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>r 0.162</td>
<td>p 0.311</td>
<td>S -0.217</td>
<td>D -0.105</td>
<td>H -0.145</td>
<td>A -0.100</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Empathy</td>
<td>r 0.266</td>
<td>p 0.093</td>
<td>S -0.059</td>
<td>D -0.085</td>
<td>H -0.091</td>
<td>A -0.073</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Supportiveness</td>
<td>r 0.275</td>
<td>p 0.081</td>
<td>S -0.214</td>
<td>D -0.174</td>
<td>H 0.036</td>
<td>A -0.361</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>r -0.007</td>
<td>p 0.967</td>
<td>S 0.015</td>
<td>D 0.060</td>
<td>H 0.487</td>
<td>A -0.026</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>r -0.348</td>
<td>p 0.026</td>
<td>S 0.293</td>
<td>D 0.197</td>
<td>H 0.214</td>
<td>A 0.221</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Spearman's rho*
3.4.2 RELATIONSHIP BETWEEN PARTNER-ASSESSED COMMUNICATION VARIABLES AND PARTNER DISTRESS

**Time-1**

Partners were not assessed on the helpfulness or effectiveness of talking to their partners (i.e. the patients), nor the perceived empathy of their partners. However, they were assessed on variables concerning the supportiveness, criticism and withdrawal of their partner. As can be seen from Table 12, there were a number of significant associations at Time-1 between these communication variables and the level of partners’ psychological distress. The more critical and less supportive the patient, the more the partner experienced feelings of hostility. Partner criticism was also associated with lower self-esteem, and higher SCL and HAD depression scores. Finally partner withdrawal was associated with higher SCL-Anxiety and SCL and HAD depression scores.

**TABLE 12: Correlation Matrix between Partner-assessed Communication and Psychological Variables at Time-1 (N=42)**

<table>
<thead>
<tr>
<th></th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(14) Supportiveness</td>
<td>r = .079</td>
<td>-.238</td>
<td>-.108</td>
<td>-.369</td>
<td>-.132</td>
<td>-.259</td>
</tr>
<tr>
<td></td>
<td>p = .617</td>
<td>.130</td>
<td>.495</td>
<td>.016</td>
<td>.404</td>
<td>.098</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>r = -.321</td>
<td>.253</td>
<td>.329</td>
<td>.566</td>
<td>.253</td>
<td>.446</td>
</tr>
<tr>
<td></td>
<td>p = .038</td>
<td>.105</td>
<td>.034</td>
<td>.000</td>
<td>.105</td>
<td>.003</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>r = .024</td>
<td>.420</td>
<td>.338</td>
<td>.116</td>
<td>.263</td>
<td>.430</td>
</tr>
<tr>
<td></td>
<td>p = .882</td>
<td>.006</td>
<td>.029</td>
<td>.464</td>
<td>.092</td>
<td>.004</td>
</tr>
</tbody>
</table>

*Spearman’s rho

**Time 2**

At Time-2 there were more pronounced associations between the partner’s psychological state and their perceptions of the patient’s behaviour (Table 13). Supportiveness was associated with lower SCL and HAD anxiety scores as well as lower SCL depression and hostility scores. Criticism was positively associated with anxiety, depression and hostility on both measures, while partner withdrawal was more weakly associated with SCL anxiety and hostility.
### TABLE 13: Correlation Matrix between Partner-assessed Communication and Psychological Variables at Time-2 (N=42)

<table>
<thead>
<tr>
<th>(14) Supportiveness</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>r</strong></td>
<td>.182</td>
<td>-.457</td>
<td>-.487</td>
<td>-.444</td>
<td>-.445</td>
<td>-.136</td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.248</td>
<td>.002</td>
<td>.001</td>
<td>.003</td>
<td>.003</td>
<td>.389</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(15) Partner criticism</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>r</strong></td>
<td>-.136</td>
<td>.413</td>
<td>.441</td>
<td>.505</td>
<td>.354</td>
<td>.334</td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.389</td>
<td>.007</td>
<td>.003</td>
<td>.001</td>
<td>.021</td>
<td>.031</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(16) Partner withdrawal</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>r</strong></td>
<td>.059</td>
<td>.329</td>
<td>.220</td>
<td>.362</td>
<td>.239</td>
<td>.004</td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.708</td>
<td>.033</td>
<td>.162</td>
<td>.019</td>
<td>.127</td>
<td>.979</td>
</tr>
</tbody>
</table>

*Spearman's rho

### 3.4.3 ASSOCIATION BETWEEN PATIENT-ASSESSED COMMUNICATION AT TIME-1 AND PATIENT DISTRESS AT TIME-2

The correlation matrix in Table 14 suggests that certain partner communication behaviours may be predictive of psychological distress among patients. The strongest association was found between “talking about one’s feelings” at Time-1 and lower HAD-Anxiety (p=0.005) at Time-2, while partner empathy at Time-1 was associated with higher self-esteem at Time-2. The other statistically significant correlation was between partner criticism at Time-1 and patient hostility at Time-2.

### TABLE 14: Correlation Matrix between Patient-assessed Communication Variables at Time-1 and Psychological Variables at Time-2 (N=42)

<table>
<thead>
<tr>
<th>TIME-1 →</th>
<th>TIME-2 →</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) Talked about concerns</td>
<td><strong>r</strong></td>
<td>-.124</td>
<td>.148</td>
<td>.052</td>
<td>.076</td>
<td>-.058</td>
<td>.013</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.439</td>
<td>.350</td>
<td>.742</td>
<td>.634</td>
<td>.714</td>
<td>.934</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td><strong>r</strong></td>
<td>.052</td>
<td>-.176</td>
<td>-.170</td>
<td>.172</td>
<td>-.427</td>
<td>-.220</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.745</td>
<td>.264</td>
<td>.281</td>
<td>.275</td>
<td>.005</td>
<td>.161</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td><strong>r</strong></td>
<td>-.092</td>
<td>.085</td>
<td>-.044</td>
<td>-.054</td>
<td>.090</td>
<td>-.067</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.566</td>
<td>.551</td>
<td>.782</td>
<td>.736</td>
<td>.571</td>
<td>.672</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td><strong>r</strong></td>
<td>.238</td>
<td>-.075</td>
<td>-.173</td>
<td>-.090</td>
<td>-.047</td>
<td>-.232</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.134</td>
<td>.635</td>
<td>.274</td>
<td>.569</td>
<td>.767</td>
<td>.140</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td><strong>r</strong></td>
<td>-.006</td>
<td>.064</td>
<td>.087</td>
<td>-.083</td>
<td>.093</td>
<td>-.022</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.970</td>
<td>.685</td>
<td>.585</td>
<td>.601</td>
<td>.559</td>
<td>.891</td>
</tr>
<tr>
<td>(10) Empathy</td>
<td><strong>r</strong></td>
<td>.380</td>
<td>-.139</td>
<td>-.198</td>
<td>-.173</td>
<td>-.156</td>
<td>-.239</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.014</td>
<td>.378</td>
<td>.209</td>
<td>.275</td>
<td>.324</td>
<td>.127</td>
</tr>
<tr>
<td>(14) Supportiveness</td>
<td><strong>r</strong></td>
<td>-.025</td>
<td>.031</td>
<td>.083</td>
<td>.025</td>
<td>.005</td>
<td>-.106</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.876</td>
<td>.848</td>
<td>.603</td>
<td>.876</td>
<td>.977</td>
<td>.503</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td><strong>r</strong></td>
<td>-.112</td>
<td>.243</td>
<td>.157</td>
<td>.369</td>
<td>.106</td>
<td>.129</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.487</td>
<td>.121</td>
<td>.321</td>
<td>.016</td>
<td>.504</td>
<td>.414</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td><strong>r</strong></td>
<td>-.108</td>
<td>.222</td>
<td>.152</td>
<td>.000</td>
<td>.198</td>
<td>.273</td>
</tr>
<tr>
<td></td>
<td><strong>P</strong></td>
<td>.500</td>
<td>.158</td>
<td>.338</td>
<td>.998</td>
<td>.209</td>
<td>.080</td>
</tr>
</tbody>
</table>

*Spearman's rho
3.4.4 ASSOCIATION BETWEEN PARTNER-ASSESSED COMMUNICATION AT TIME-1 & PARTNER DISTRESS AT TIME-2

A similar correlational analysis was conducted for the psychological distress of partners at Time-2 (Table 15). Criticism by the patient at Time-1 was predictive of psychological distress among partners at Time-2 on all measures. It was particularly associated with depression: correlations of 0.530 with SCL-Depression (p<0.001) and 0.455 with HAD-Depression (p=0.002). Supportiveness did not predict psychological distress although patient withdrawal was correlated with SCL anxiety, depression and hostility.

<table>
<thead>
<tr>
<th>TIME-1 ↓</th>
<th>TIME-2 →</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(14) Supportiveness</td>
<td>r</td>
<td>-.057</td>
<td>-.242</td>
<td>-.137</td>
<td>-.261</td>
<td>-.134</td>
<td>.013</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td>.721</td>
<td>.123</td>
<td>.386</td>
<td>.095</td>
<td>.397</td>
<td>.936</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>r</td>
<td>-.344</td>
<td>.347</td>
<td>.530</td>
<td>.396</td>
<td>.342</td>
<td>.455</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td>.026</td>
<td>.024</td>
<td>.000</td>
<td>.009</td>
<td>.027</td>
<td>.002</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>r</td>
<td>.100</td>
<td>.329</td>
<td>.317</td>
<td>.354</td>
<td>.293</td>
<td>.262</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td>.529</td>
<td>.033</td>
<td>.041</td>
<td>.022</td>
<td>.080</td>
<td>.093</td>
</tr>
</tbody>
</table>

*Spearman’s rho

3.4.5 ASSOCIATION BETWEEN RELATIONSHIP VARIABLES AT TIME-1 AND PSYCHOLOGICAL DISTRESS AT TIME-2

Because there were no statistical differences between the video and control groups on relationship variables at Time-1, their scores were combined.

Patients

While patient subjects’ scores on the Dyadic Adjustment Scale at Time-1 were inversely related to their scores on SCL-Depression and SCL-Hostility at Time-2, there was also a paradoxical positive association between the patient’s perception that the relationship had improved and their HAD-Anxiety scores (Table 16). No other significant relationships were observed.
TABLE 16: Correlation Matrix between Relationship Variables at Time-1 and Psychological Variables at Time-2 among Patients

<table>
<thead>
<tr>
<th>TIME-1 ↓</th>
<th>TIME-2 →</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(13) Relationship change</td>
<td>r</td>
<td>-.234</td>
<td>.281</td>
<td>.248</td>
<td>-.087</td>
<td>.345</td>
<td>.155</td>
</tr>
<tr>
<td>p</td>
<td>.142</td>
<td>.071</td>
<td>.113</td>
<td>.584</td>
<td>.025</td>
<td>.327</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>41</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>r</td>
<td>.081</td>
<td>-.094</td>
<td>-.054</td>
<td>-.021</td>
<td>.076</td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>.617</td>
<td>.969</td>
<td>.555</td>
<td>.732</td>
<td>.895</td>
<td>.632</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>41</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>18) Dyadic Adjustment Scale</td>
<td>r</td>
<td>.264</td>
<td>-.282</td>
<td>-.335</td>
<td>-.429</td>
<td>-.218</td>
<td>-.284</td>
</tr>
<tr>
<td>p</td>
<td>.096</td>
<td>.071</td>
<td>.030</td>
<td>.005</td>
<td>.166</td>
<td>.068</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>41</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>r</td>
<td>.142</td>
<td>-.095</td>
<td>-.194</td>
<td>-.054</td>
<td>-.054</td>
<td>-.139</td>
</tr>
<tr>
<td>p</td>
<td>.375</td>
<td>.549</td>
<td>.219</td>
<td>.736</td>
<td>.733</td>
<td>.379</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>41</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
</tbody>
</table>

*Spearman's rho

Partners

Among partners, scores on the Dyadic Adjustment Scale at Time-1 were inversely related to SCL-Hostility and HAD-Anxiety at Time-2 but these were the only statistically significant results (Table 17).

TABLE 17: Correlation Matrix between Relationship Variables at Time-1 and Psychological Variables at Time-2 among Partners

<table>
<thead>
<tr>
<th>TIME-1 ↓</th>
<th>TIME-2 →</th>
<th>Self-Esteem</th>
<th>SCL Anxiety</th>
<th>SCL Depression</th>
<th>SCL Hostility</th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>(13) Relationship change</td>
<td>r</td>
<td>.131</td>
<td>-.129</td>
<td>-.199</td>
<td>-.154</td>
<td>-.090</td>
<td>-.037</td>
</tr>
<tr>
<td>p</td>
<td>.409</td>
<td>.414</td>
<td>.205</td>
<td>.331</td>
<td>.571</td>
<td>.818</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>(17) Happiness of relationship</td>
<td>r</td>
<td>.117</td>
<td>-.081</td>
<td>-.204</td>
<td>-.121</td>
<td>-.132</td>
<td>-.268</td>
</tr>
<tr>
<td>p</td>
<td>.460</td>
<td>.565</td>
<td>.195</td>
<td>.444</td>
<td>.404</td>
<td>.086</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>18) Dyadic Adjustment Scale</td>
<td>r</td>
<td>.054</td>
<td>-.118</td>
<td>-.200</td>
<td>-.319</td>
<td>-.316</td>
<td>-.192</td>
</tr>
<tr>
<td>p</td>
<td>.732</td>
<td>.458</td>
<td>.205</td>
<td>.039</td>
<td>.041</td>
<td>.223</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Significant Others Scale</td>
<td>r</td>
<td>.029</td>
<td>.049</td>
<td>.084</td>
<td>-.157</td>
<td>.054</td>
<td>.013</td>
</tr>
<tr>
<td>p</td>
<td>.856</td>
<td>.759</td>
<td>.603</td>
<td>.326</td>
<td>.737</td>
<td>.935</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>41</td>
<td>41</td>
<td>41</td>
<td>41</td>
<td>41</td>
<td>41</td>
<td></td>
</tr>
</tbody>
</table>

*Spearman's rho
3.5 Gender Differences

In order to investigate gender differences in the preferred source of support, comparisons were made between men and women. Females were chosen more often as the preferred supporter by both men and women. 65% of those who responded to this question (n=87) designated a female as their primary source of support since the cancer diagnosis, compared with only 33% designating a male (Chi-square=9.33, 1 df, p=0.002). Table 18 presents the gender of the preferred supporter by the gender of the subject. 39 (95%) of the 41 men (who were specific) designated a female, while only 27 (60%) of the 45 women who responded chose a male. This is significantly different (Pearson chi-square = 29.183, p< 0.001).

<table>
<thead>
<tr>
<th>Gender of preferred helper</th>
<th>MALE SUBJECTS n(%)</th>
<th>FEMALE SUBJECTS n(%)</th>
<th>TOTAL n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both</td>
<td>1 (2)</td>
<td>0</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Female</td>
<td>39 (93)</td>
<td>18 (40)</td>
<td>57 (65)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (5)</td>
<td>27 (60)</td>
<td>29 (33)</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>45</td>
<td>87</td>
</tr>
</tbody>
</table>

Among patients, 21 (95%) of the 22 men who responded to this question chose their partners, while 16 (73%) of the 21 females patients specified their partners as their most important source of support (chi-square = 3.32, 1 df, p = 0.068). Among partners, 13 (68%) of the 19 men who responded designated their partners, while only 8 (36%) of the 22 females chose their partners (chi-square = 4.19, 1 df, p= 0.041). Overall, 56% of female subjects and 83% of male subjects chose their partners (chi-square=5.84,1 df, p=0.016). These findings support the hypothesis that males are more likely than females to perceive their spouses as their most important source of support.
3.5.1 EFFECT OF THE VIDEO INTERVENTION ON FEMALES’ PERCEPTION OF MOST IMPORTANT SUPPORT

It was hypothesised that the intervention would lead more females to regard their spouses as their most important source of support. Female subjects in the two groups were compared as to whether or not they regarded their partner as their most important source of support at both time points. Table 19 summarises these changes. Although there were four more women in the video group at Time-2 who regarded their partners as their most important source of support to their partners and one less woman in the control group, this difference did not achieve statistical significance.

<table>
<thead>
<tr>
<th></th>
<th>VIDEO (N)</th>
<th>CONTROL (N)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>TIME 1</td>
<td>9 (21) 43%</td>
<td>16 (20) 80%</td>
<td>3.102</td>
<td>0.212</td>
</tr>
<tr>
<td>TIME 2</td>
<td>13 (21) 62%</td>
<td>15 (20) 75%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.5.2 GENDER DIFFERENCES IN THE PERCEPTION OF PARTNER COMMUNICATION

Male and female patients were compared on each of the communication variables to investigate the hypothesis that female patients will perceive their spouses to communicate lower empathy and supportiveness and higher criticism and withdrawal than male patients. The results of these comparisons are presented in Table 20. Male patients perceived their partners to be significantly more empathic (p = 0.002) than female patients. There was a strong, albeit non-significant, tendency for male patients to perceive their partners as more supportive than female patients (p = 0.055). Both these findings lend some support for the hypothesis. However, there was no support for the hypothesis that female patients would experience their partners as more critical and withdrawn than male patients.
### TABLE 20: Gender Differences in Patients’ Perception of Partner communication at Time-1

<table>
<thead>
<tr>
<th></th>
<th>MALES</th>
<th></th>
<th>FEMALES</th>
<th></th>
<th>MANN-WHITNEY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>MEAN</td>
<td>sd</td>
<td>N</td>
<td>MEAN</td>
</tr>
<tr>
<td>(3) Talked about concerns</td>
<td>22</td>
<td>2.11</td>
<td>1.08</td>
<td>22</td>
<td>2.17</td>
</tr>
<tr>
<td>(4) Talked about feelings</td>
<td>21</td>
<td>2.51</td>
<td>1.19</td>
<td>22</td>
<td>2.10</td>
</tr>
<tr>
<td>(5) Helpfulness of talking</td>
<td>22</td>
<td>0.32</td>
<td>.66</td>
<td>20</td>
<td>1.10</td>
</tr>
<tr>
<td>(6) Effectiveness of talking</td>
<td>22</td>
<td>13.09</td>
<td>5.51</td>
<td>20</td>
<td>13.00</td>
</tr>
<tr>
<td>(8) Holding back</td>
<td>22</td>
<td>0.5</td>
<td>.67</td>
<td>22</td>
<td>0.95</td>
</tr>
<tr>
<td>(10) Empathy</td>
<td>22</td>
<td>18.68</td>
<td>7.10</td>
<td>22</td>
<td>9.18</td>
</tr>
<tr>
<td>(14) Supportiveness</td>
<td>22</td>
<td>5.05</td>
<td>5.58</td>
<td>23</td>
<td>3.43</td>
</tr>
<tr>
<td>(15) Partner criticism</td>
<td>21</td>
<td>0.57</td>
<td>.93</td>
<td>23</td>
<td>0.37</td>
</tr>
<tr>
<td>(16) Partner withdrawal</td>
<td>21</td>
<td>0.14</td>
<td>.36</td>
<td>23</td>
<td>0.22</td>
</tr>
</tbody>
</table>

*two-tailed tests*

### 3.6 Initial Video Feedback

The initial video feedback questionnaire (Appendix E) was primarily designed to enhance the effect of the video by helping subjects personalise and internalise its messages. In light of the high level of endorsement of the importance, relevance and potential helpfulness of the video’s main themes, the responses indicate that the video intervention was perceived as credible by the participants who saw it. Table 21 summarises these responses which were made on a visual analogue scale ranging from 0 (Not at all…) to 10 (Extremely…).
"The video is concerned with the problems of giving support within a relationship when one partner has cancer"
Table 23 presents findings on the perceived helpfulness of the video. This indicates that the majority of subjects felt that the video had caused them to talk more as a couple. A small majority also believed that the video had caused them to support their partner more, though a similar majority believed that the video had not caused their partner to support them more. The vast majority of subjects (89%) believed that the video should be given to other couples when one of them has cancer and only one subject (a male partner) believed it should not, though this subject had, in fact, endorsed the video as having been extremely helpful on all measures and believed that it had led him and his partner to support each other more.

| TABLE 23: Follow-up Video Questionnaire – Perceived Effect of Watching Video: 1 |
|---------------------------------|-------|-------|-------|-------|-------|
|                                | PATIENTS (n=11) | PARTNERS (n=8) | TOTAL (%) |
| Do you believe that the video caused you both to talk more? | YES | 7 | 4 | 4 | 6 | 21 (58) |
|                                | NO  | 4 | 4 | 4 | 3 | 15 (42) |
| Do you believe that watching the video led you to support your partner more? | YES | 6 | 5 | 3 | 5 | 19 (53) |
|                                | NO  | 5 | 3 | 5 | 4 | 17 (47) |
| Do you believe that watching the video led your partner to support you more? | YES | 5 | 5 | 3 | 3 | 16 (44) |
|                                | NO  | 6 | 3 | 5 | 6 | 20 (56) |
| Do you believe that a video like this should be given to other couples when one of them has cancer? | YES | 9 | 8 | 7 | 7 | 31 (89) |
|                                | NO  | 0 | 0 | 1 | 0 | 1 (3) |
|                                | MAYBE | 2 | 0 | 0 | 1 | 3 (8) |

The visual analogue scale responses (Table 24) revealed little information about the relative merits of different components of the video though males appeared to find the advice of the expert somewhat more helpful than females.
<table>
<thead>
<tr>
<th>How helpful was..</th>
<th>Males mean</th>
<th>Females mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>The advice on the video</td>
<td>7.16</td>
<td>7.36</td>
</tr>
<tr>
<td>Hearing the patients' experiences</td>
<td>7.53</td>
<td>7.79</td>
</tr>
<tr>
<td>The advice of the 'expert'</td>
<td>8.32</td>
<td>7.77</td>
</tr>
<tr>
<td>The leaflet that came with the video</td>
<td>7.22</td>
<td>7.21</td>
</tr>
</tbody>
</table>

(Visual Analogue Scale: 0 = Not at all..., 10 = Extremely...)
4. DISCUSSION

4.1 Review of Research Aims

4.1.1 STUDY AIM 1

To examine gender differences in the ability to communicate emotional and confiding support between partners and to measure the effect of this support on psychological adjustment

The Couple Relationship

The first aim of this study was an attempt to extend the work of Pistrang and Barker (1992, 1995) who studied the nature of informal support obtained by women with breast cancer, but to build on this earlier work by adding the male patient and female partner perspective. Pistrang and Barker had found that women felt less understood by their partner than by friends and relatives and that, ideally, they would have liked to have talked more to him but held back from talking about their feelings in an effort to protect him. In fact, nearly 40% of the sample had changed their nomination from their partners to someone else following their cancer. Although the present study did not obtain retrospective data on the choice of main supporter before the diagnosis of cancer, it did find that female subjects were less likely than male subjects to designate their partner as their main source of support. Furthermore, at Time-1 (11 weeks after their cancer diagnosis), 5 female and one male patient in the current study reported that they would like to have talked more to their partners, and there was a correspondingly stronger tendency for women to hold back from talking about their feelings than men (though this did not achieve statistical significance).

In their cross-sectional study, Pistrang and Barker had found that greater relationship satisfaction and helpfulness of disclosure were associated with lower psychological distress. The present prospective study also found that
relationship satisfaction at Time-1 (when measured by the Dyadic Adjustment Scale) was negatively associated with depression and hostility among patients, and hostility and anxiety among partners.

The fact that the Dyadic Adjustment Scale was more predictive than the other relationship measures may be because it includes reflective items about the quality of the relationship (e.g. "How often do you discuss or have you considered divorce, separation, or terminating your relationship?"), items which may have more accurately tapped historically negative aspects of the relationship. This seems likely since, interestingly, the only communication variables consistently associated with later psychological distress tended to be the negative ones of partner withdrawal and criticism. This was particularly evident among partners which was an unexpected finding. One might speculate that carers who experience their patient-partners as consistently withdrawn and critical are apt to feel both that they are failing in their roles as carers as well as feeling increasingly helpless to alter the situation. This confirms earlier reports which suggested that negative behaviours within close relationships have a stronger influence over mental health than positive ones (Manne, Taylor, Dougherty and Kemeny, 1997; Schulz, Schulz, Schulz and von Kerekjarto, 1996) and that a "contagion of distress" (Bolger et al, 1996) may ultimately lead to an erosion of support.

In view of the large number of correlations conducted in this study, some caution should be exercised in interpreting the statistically significant results. In particular no direction of causality can be assumed from the data. As in Pistrang and Barker's study, helpfulness of disclosure was associated with lower distress among patients at Time-2, though the effectiveness of talking to one's partner at Time-2 was more consistently associated with psychological well-being at that time. In addition, the extent to which patients felt that they were able to talk about their feelings at Time-1 was negatively associated with HAD-Anxiety at Time-2. There were also statistically significant associations between
partner empathy at Time-1 and the patient’s self-esteem at both Time-1 and Time-2.

These findings suggest that the effect of partner empathy for patients with cancer is to bolster their self-esteem, while talking to their partners, if this is experienced as effective and helpful, affords some protection to their mental health. Among partners, the experience of lack of support, criticism and withdrawal by the patient is associated with higher levels of distress though only criticism and withdrawal were predictive of later distress (though it should be noted that partners’ perceptions were not assessed for all communication variables).

**Gender Differences**

Female participants were significantly less likely than male participants to choose their partner as their main source of support. This finding was congruent with the fact that male patients assessed their partners as significantly more empathic than female patients, and a similar trend was found for perceived supportiveness though this did not quite achieve statistical significance. It also supports Pistrang and Barker’s contention that men may have difficulty in communicating about feelings when attempting to support their partners (Pistrang and Barker, 1992).

Criticism and withdrawal did not differentiate men and women’s communication behaviour, as had been found in previous studies of cancer patients (Manne, Taylor, Dougherty and Kemeny, 1997), arthritis patients (Manne and Zautra, 1989) and healthy couples (Fincham, Beach, Harold and Osborne, 1997). Both variables were assessed with a single 5-point scale which may have been too crude to detect differences between the genders. Previous authors (e.g. Manne and Zautra, 1989) have used several items to assess criticism. In fact, a number of qualitative responses to the question “How do you think the illness or treatment has affected your partner?” appeared to support the contention that men may have been more withdrawn. None of the male comments referred to
their partners having withdrawn, but the female comments included such statements as:

At times not himself – distant, withdrawn, insecure, easily upset.

As he takes things inwardly it will take time for it to surface.

Very difficult to tell because he is a very deep person, keeps things to himself.

I think he is worried about me, but he is unable to cope with illness, so just blanks it out and gets on with his life as if nothing has happened.

Nearly all the men in this study nominated a woman as their most important source of support since the cancer diagnosis, while approximately two-thirds of women chose a man. 56% of the women chose their partners as their most important source of support compared with 83% of men. In the Pistrang and Barker study of female breast cancer patients 51% chose their partner as their main source of support. When the patients in the present study were examined separately, 95% of men and 73% of women chose their partner as their preferred supporter, the latter being a considerably higher figure than in the all-female Pistrang and Barker study.

When partners were examined separately, 68% of men and 36% of women chose their partners (i.e. patients) as their preferred helper, somewhat lower proportions and a wider gender discrepancy than that reported by Keller, Henrich, Sellsschopp and Beutel (1996) who obtained figures of 76% and 56% for men and women respectively. The more striking finding, however, was that 90% of male partners designated a female as their primary source of support while only 43% of female partners chose a man. Thus, confirming earlier studies (Northouse, Jeffs, Cracchiolo-Caraway, et al, 1995; Omne-Pontén,
Holmberg, Sjödén and Bergström, 1995), it seems that, whether in the role of patient or partner, men turn to the women in their lives, especially their partners, considerably more often than women turn to men.

There are a number of ways in which gender differences have been conceptualised in the literature and some consideration will now be given to these. There is currently growing interest in the development of caring and supportive behaviour. Within the field of personal relationships, there is evidence that comforting skills are developed in a progressive manner throughout childhood and adolescence and are influenced by parental behaviour. These skills are thought to reflect the developing cognitive structures which are used to interpret and represent the social world (Burleson, 1990). Similarly, the development of self-identity in early infancy, while involving the distinguishing of self from other, is inherently a ‘relational self’: young babies are receptive and responsive to social stimulation (Barrett, 1997). Therefore, it may be helpful to look at developmental theories to explain gender differences in empathic support.

From a feminist psychoanalytic perspective, Dorothy Dinnerstein has argued that the historical division of labour between female caring in the private world and male acting in the public world stems from “the mother’s power to foster or forbid, to humble or respect, our first steps toward autonomous activity” (Dinnerstein, 1976, p. 165). While early Freudian theory about gender differences rested on biological determinism, more modern theorists, like Dinnerstein, have argued that women’s more intimate relationship with child-rearing leads boys and girls to resolve their fear of maternal domination and need for individuation in ways which reinforce the status quo.

From the perspective of moral development, Gilligan (1982) has built on Dinnerstein’s work and particularly that of Chodorow (1978) and has argued that males and females develop different ethics based on different conceptions of maturity which, again, are born from the central position of women in child-
rearing. For the male, the focus is on individuation, autonomy and individual achievement while, for the female, the concern is with relationships. Boys develop a morality based on rights, while girls develop an ethic of responsibility for others. Furthermore, “since masculinity is defined through separation while femininity is defined through attachment, male gender identity is threatened by intimacy while female gender identity is threatened by separation” (Gilligan, 1982, p.8). Girls are socialised to develop a language of emotion, relationships and care while, generally, boys are not.

There is also a growing interest in the application of Attachment Theory (Bowlby, 1988) to adult relationships, though rarely has the issue of gender been the focus. However, Crowell (1998) has recently argued that adult attachment is a function of three factors: childhood attachment relationships, previous peer-to-peer relationships, and the history of the current relationship (e.g. the partner relationship which may itself strongly resonate with childhood attachment relationships). Her research has revealed that men’s adult sense of security is more related to their early attachment relationships (e.g. mother) than that of women for whom their current relationship (e.g. spouse) tends to be the more important influence. This finding is consistent with Gilligan’s thesis that men’s preoccupation with autonomy leads them to place less value on current relationships. Indeed, couple therapists, drawing on attachment and psychoanalytic theory, have argued that for a relationship to be mature and creative requires that the couple has a capacity for self-reflection and that the individuals within it are able to give up earlier notions of independence and self-sufficiency (Morgan and Ruszczynski, 1998).

There is little doubt that the threat posed by a life-threatening illness such as cancer invokes powerful dependency feelings and, in attachment theory terms, an urgent need to return to the secure base of one’s primary attachment figure (Bowlby, 1979). Yet, the present study’s finding that, in such a situation, men turn to women more than women turn to men appears to contradict Gilligan’s thesis and Crowell’s findings.
It will be recalled that Pistrang and Barker (1992) found that communication problems were largely to do with “men’s difficulties dealing with feelings” rather than an inability to understand the woman’s concerns, an observation which is consistent with the findings of the current study and with Gilligan’s contention that men’s identity is threatened by intimacy. It is thus conceivable that, when confronted by cancer, men predominantly turn to their current representation of their early attachment relationship, their partners. In fact, it is likely that men’s dependency needs have long been met by their partners but the acknowledgement of this fact would be to threaten the man’s precarious sense of themselves as autonomous ‘mature’ adults. Women, meanwhile, predominantly turn to their primary adult attachment figure which they perceive to be their husbands. However, as Pistrang and Barker found, women are sometimes disappointed by their spouses’ capacity for intimacy and empathy and turn instead to other females for support. Their assumptions about attachment are ‘shattered’. Indeed, if men have not developed an ethic of care to the same extent as women, as Gilligan contends, then they are less likely to have developed or practised the interpersonal skills of caring and comfort described by workers in the field of personal relationships, or those of empathy and supportiveness as observed in the current study.

The qualitative responses to the Initial Video Feedback questionnaire give a flavour of some of the men’s difficulties concerning the language of emotion. The following comments were made by women to the Health Belief Model-derived question: What barriers or obstacles, if any, do you see preventing you and your partner following the advice in this video? There were no similar comments made by men about women.

My partner does not usually express his feelings or discuss things.

My partner finds it hard to express his feelings and though I am ready to listen, he cannot put it into words how he feels.
My partner does not always take advice if he thinks he is right, he does not compromise.

He sometimes finds it hard to tell me how he feels, especially when he knows it may upset me.

To conclude, this study found differences between men and women's perceptions of their partners' behaviour. These differences are largely consistent with previous studies which suggest that men demonstrate less empathy and support than women in equivalent roles though there was no evidence of a gender difference in negative behaviours such as criticism or withdrawal. However, some authors have speculated that, although women may perceive less support in the marital relationship, they may be more responsive to the support that is provided within an intimate relationship. Women may be more aware of relationship difficulties than men and may be more likely to report negative spouse behaviour. (Manne, Taylor, Dougherty, and Kemeny, 1997).

4.1.2 STUDY AIM 2

To devise and evaluate a preventive intervention designed to enhance the mutual provision of social support between patients and their partners.

Responses to the initial video feedback questionnaire showed that subjects who watched the video largely endorsed its message and regarded it as relevant to their relationship. Follow-up data indicated that video group subjects had watched the video and that eight subjects claimed to have watched it three times. Most subjects believed that the video had caused them and their partner to talk more and had led them to support their partner more, and the vast majority of subjects felt that the video should be given to other couples facing cancer. Qualitative responses to the Initial Video Feedback questionnaire also reinforced the impression that subjects found the video helpful.

The video was very helpful, especially to remind me not to be critical.
The video we found was so real to us, was very grateful for the viewing (sic).

I felt I could have been any one of these women talking.

Very helpful – hopefully this will make us talk about our feelings and help us to be together.

Qualitative information from the Follow-up Video Feedback questionnaire also supported this view. For example, a male partner expressed his support for the video thus:

I was already aware that my wife thought that I had not been particularly supportive. Even before the cancer I often felt that she expected me to be clairvoyant in recognising her needs and changes. The video helped us discuss this and for me to express that I often did not know what she wanted from me.

However, despite evidence that subjects had watched the video and found it credible, the outcome measures offered little empirical support for the effectiveness of the video in enhancing couple support.

In comparison with the no-video control condition, the video appeared to have little impact on key outcome variables. There were no significant differences between the groups among partner subjects on any measure of communication, relationship quality or psychological distress. However, there was a significant decline among video group partners in the perceived supportiveness of their partners from Time-1 to Time-2, raising the disquieting possibility that the video had either led patients to become less supportive, and/or partners to feel less supported. This finding was indirectly supported by a significant reduction in HAD-Anxiety among control group partners with no corresponding reduction among video group partners.

There were only two statistically reliable differences between the groups among patient subjects. Patient ratings of partner supportiveness declined somewhat in both groups but significantly less in the video than in the control group, whilst
perceived happiness increased significantly more in the video than in the control group. In fact, patients in the control group showed a significant decrease in perceived partner support, and an increase in both hostility and depression from Time-1 to Time-2. While these findings may suggest that the video offered some protection against the development of these problems, they were isolated findings which are potentially unreliable due to the number of significance tests undertaken in the analysis.

The fact that the majority of the outcome variables generated data in the predicted direction offers some encouragement, but consistency of this sort is not sufficient to draw reliable conclusions; only a larger sample size could confirm these trends. The finding of decreases in HAD-Depression scores from Time-1 to Time-2 among video group patients with corresponding increases among the control group was encouraging. However, on this measure randomisation had failed: the video group had significantly higher HAD-Depression scores at Time-1; thus one is unable to draw any reliable conclusion on the basis of this finding.

The possible reasons for these findings and the methodological weaknesses of the study will now be examined. They are presented together because the issues are intimately related.

4.2 Limitations and Weaknesses of the study

4.2.1 DESIGN

Ideally, this study should have included a control video. Furthermore, the Time-1 questionnaires were likely to have biased participants to be more vigilant about their relationship. Thus, a control intervention might have refocused their attention on other issues, while controlling for the non-specific effect of receiving a video. Since it would be ethically dubious to provide a placebo video to couples at such a vulnerable time in their lives, a relaxation control video was
made in parallel with the experimental video (see Note 2, page 131) though was abandoned due to the slow accrual of participants.

4.2.2 MEASURES

The measures used were largely appropriate to the research questions and were successfully piloted. However, like all self-report questionnaires, they provide only an indirect measure of the behaviours in question. An interview format could have yielded qualitatively richer data but would have been more vulnerable to response biases. An observational study of the communication patterns within couples would also have yielded more fine-grain detail, but again would be subject to response bias and would be highly intrusive given the distressing circumstances facing the couple. As there was no direct contact between the author and the subjects, it was hoped that responses were not unduly biased (e.g. by social desirability).

Most of the measures had been used before in similar studies, particularly those of Pistrang and Barker (1992, 1995) even though some of the questions had unknown reliability, albeit good face validity. Unlike these earlier studies, this one used a prospective design and it was hoped that the measures would be sensitive to change over time. However, exactly as Pistrang and Barker noted in their study, the qualitative feedback often indicated greater difficulties within relationships than were indicated in the questionnaire responses: “While women were willing to talk about the problems, they were loath to commit themselves, in numbers, to negative evaluations of their partners” (Pistrang and Barker, 1995, p.794).

Furthermore, items on some measures turned out to be ambiguous and had to be discarded. For example, on question 9, patients were asked to rate how much they agreed with the following statements: “I’ve held back from talking to my partner about my concerns and feelings to do with my illness because... (a) I don’t want to worry him/her...” and “(c) I don’t want to upset him/her.” Agreement with these very similar items could be regarded as positive or
negative depending on the nature of the relationship and the meaning ascribed to “worry” and “upset”.

4.2.3 RANDOMISATION
Randomisation was conducted through the process of sequential allocation in order to achieve similar numbers of male and females in the intervention and control groups. Whilst the video and control groups were similar in the majority of respects, randomisation failed in several important areas, seeming to bias against the video group which had lower scores on partner empathy, and higher scores on depression and hostility. In addition, 83% of the control group, over twice as many as those in the video group, had previously coped with a family history of cancer. This may have led them to resume coping strategies which they had previously found effective and which may have afforded them some protection against the stress of their situation.

4.2.4 SAMPLE SIZE AND RECRUITMENT
An audit of new patients attending the four hospitals where subjects were recruited for this study revealed that 323 married patients were newly diagnosed with colorectal cancer in 1996. This led the author to conclude with some confidence that recruitment would pose few problems. However, in just over ten months only 80 eligible couples had been identified by clinic staff and of these only 46 couples were successfully recruited.

The fact that only 57% of the 80 eligible couples agreed to participate raises the question of how representative the sample was of the general population. Although the age and gender of those who refused was not different from those who took part, it is conceivable that they were more distressed and unwilling to cope with the perceived added stress of a research project. Indeed, it is probable that couples whose relationship was struggling may have been less likely to participate in a study looking at “how couples cope”.

Nevertheless, of those who received the consent information, 70% did subsequently participate. Refusal rates of up to 80% have been noted by others studying couples affected by cancer (Keller, Henrich, Sellschopp and Beutel, 1996). The present study successfully avoided the high subject attrition which is also typical of such studies (Baider et al, 1998) by providing detailed consent information and informative letters.

The total sample reported scores on the HAD which were lower than most published figures. At Time-1 only 9.5% of all participants achieved the cut-off for “case-hood” of 11 on either the anxiety or depression subscales. This compares with reported rates of between 15 and 20% (Massie and Holland, 1990). This supports the contention that the sample may not have been representative of cancer patients generally.

A much larger sample size would have been desirable in order to draw statistically reliable conclusions about the effectiveness of the video. While the majority of the change scores were in the predicted direction, most failed to achieve statistical significance. For example, scores on perceived partner empathy went up two points in the video group but remained unchanged in the control group (p=0.225). In order to achieve a statistically reliable difference of this magnitude a sample size of approximately 54 couples in each group would be required.3

4.2.5 SAMPLE SELECTION

A fundamental issue concerns the fact that the intervention was designed to have a catalytic effect on couples faced with a particularly stressful experience: the diagnosis and treatment of cancer in one of them. Although the author had no illusions that it would have a lasting effect on the relationship of couples who

3 In order to get a Z-value of 1.2 with a sample of 20 subjects in each group up to a Z-value of 1.96 (for significance at the 5% level), a sample size of 20 (1.96/1.2)^2 = 54 is needed.
had been together for the majority of their lives, it was hoped that the video might provoke a temporary shift in the nature of the couple's style of communication leading to higher levels of support and the prevention of psychological distress.

However, a fifteen minute video is inherently a weak intervention. It is unlikely to have had any effect on couples who were already highly mutually engaged and supportive of one another. Indeed, some of the qualitative feedback confirmed the perceived redundancy of the video's message for some couples. Equally, one could speculate that the video is unlikely to have had much effect on relationships which were highly dysfunctional, unhappy or disengaged. For example, one man reported a possible barrier to following the advice in the video as being his wife's presumably long-standing 'difficult' nature: "My wife is extremely assertive with an argumentative nature, she finds it extremely hard to be compliant."

A more successful design might have been to select couples as being eligible for the study on the basis of initial scores on a measure of relationship satisfaction (e.g. the Dyadic Adjustment Scale). Those scoring very high on satisfaction could be excluded, whilst offering very low-scoring couples some form of face-to-face couple intervention. One difficulty with this approach is being able to estimate the proportion of couples falling into this "middle group", especially when recruitment may already be problematic, as was the case in this study. Alternatively, if one assumes that the video is a weak but effective intervention, it could be further evaluated by giving it to a very large sample of unselected couples (i.e. mixed cancer sites) as a preventative measure.

4.2.6 CONFOUNDING VARIABLES

While randomisation failed in several areas, another concern was the failure to control for other potentially important variables. In particular, although there were no significant differences between the groups in terms of patients' recent experience of cancer treatments either at Time-1 or Time-2, there were no
measures of physical health, severity of illness, functional ability or length of hospitalisation during and prior to the study. The latter variables may have skewed the results. For example, an increase in symptomatology among patients in the video group may have swamped the effects of the video.

The letter to couples who were sent the video (page 222) included a statement which may have been an influence on participants (in addition to the effect of the video itself): "This video is designed to help you cope, as a couple, with the stress of the medical treatment you are undergoing; I hope you find it helpful."

4.2.7 TUMOUR SITE

The choice of colorectal cancer for this study was governed by its high incidence, the fact that it is gender-neutral, and that it has rarely been the focus of psychosocial research. However, it is also a disease whose incidence correlates with age, and the resulting sample had a mean age of nearly sixty years old. Although older people are also rarely studied in psychosocial oncology, it may be that they are not the ideal group for research on relationships. The fact that couples had been married an average of 32 years bears testimony to the stability of their relationships; persistence is likely to predict marital stability since most marriages break down within the first few years and divorce decreases as the length of marriage increases. Furthermore, compared with younger people, older couples rate their marriages as happy or very happy, and are less likely to admit to experiencing either especially positive or negative feelings in their marriage (Bedford and Blieszner, 1997). In the current study this may have led to a flattening of responses and a possible ceiling effect on some relationship measures. In addition, where the relationship was poor, it may have been too entrenched to change as a result of such an intervention.

Some of the prescriptive advice may have been difficult to enact in an older population. For example, men generally have smaller social networks than
women and, as others have found (Northouse, Jeffs, Cracchiolo-Caraway, Lampman et al, 1995), rarely discuss their concerns with people outside their family. Similarly, many elderly people live in isolated conditions and have few other people on whom they can rely (Broadhead, Kaplan, James, Wagner, et al, 1983). Thus, encouraging subjects to seek additional support from outside their relationship may have been desirable but unrealistic for some subjects in this sample.

4.2.8 THE VIDEO INTERVENTION

There are a number of ways in which the video intervention was less than ideal, both in terms of form and content. At a structural level, the video began too quickly, giving the viewer insufficient time to absorb the main themes about to be discussed. At a content level there were more serious flaws.

The ex-patients on the video comprised five women and one man. A more equal balance of the sexes would have been preferable. The video patients (with the possible exception of the one man), and some of the non-speaking couples, were also considerably younger than the research subjects and, consequently, the subjects may have had difficulty identifying with the characters in the video. The video patients were predominantly middle-class and this may have also led to problems of identification for some subjects. Although the evidence for the importance of model similarity is inconclusive (Eiser and Eiser, 1996), it is likely that model-target audience congruence is generally preferable.

The video contained no testimony from the perspective of the partner. Although the “expert” on the video attempted to stress the difficulties for the partner, this message is likely to have been more powerfully delivered by someone who had fulfilled this role. Hearing about the problematic and successful experiences of a partner may have led partner subjects to feel more understood and provided them with a model to emulate.
Because the video was structured around patient testimonies, the specific messages were not as clear as they might have been using a somewhat more didactic approach. In fact, the desired behaviours were not clarified until the end of the video when the main points were summarised using captions and a voice-over. More importantly, none of the desired behaviours were modelled on the video so that subjects could see exactly what was being advocated, an issue of importance to successful video interventions (Eiser and Eiser, 1996). Instead, three women spoke about having experienced poor support while only one woman and one man spoke about having received good partner support. In view of the results, the video may have been asking male subjects to engage in supportive behaviours that they simply lacked the skills or confidence to perform; the video may have led them to feel even less competent.

4.3 Conclusions

"He was very upset but encouraged me to be positive, that he was there for me, and that we would see it through together"

(Female patient, describing her husband's reaction to her diagnosis)

This study yielded interesting and clinically useful information about gender differences in the transaction of support between partners in a relationship when one of them has been diagnosed with cancer. The Matching Hypothesis predicted that, in the context of a life-threatening illness, emotional empathic support is the optimal type of social support, and a number of empirical studies have confirmed this to be true. This study supports the view that there are gender differences in the capacity of men and women to provide this type of support. On average, men were perceived by their partners to be less empathic and supportive than women were perceived by their partners. Of course, these mean differences obscure the very real concern and empathic support shown by many men in this study towards their partners, but they nonetheless probably reflect widespread gender differences in society.
The other area of clinical relevance concerned the predictive power of the negative communication variables of criticism and withdrawal (and, to a lesser extent, the quality of the relationship). This was especially true for partners: perceiving the patient as critical or withdrawn at Time-1 was associated with later anxiety, depression, hostility and lower self-esteem. This finding supports the view that, while the couple relationship may be an important source of social support, it may constitute a source of additional stress particularly for the patient’s partner.

As others have observed, there has been a great deal of empirical research in the area of social support and cancer though little of it has been theory-driven (Keller, Henrich, Sellschopp and Beutel, 1996). The same can be said of the few studies which have specifically examined gender issues. The results of the current study have been discussed in the context of recent theoretical and empirical work drawn from attachment theory. As workers in the field of personal relationships have noted, adult relationships can only be understood in terms of the developmental history of both partners and of the relationship itself, as well as its current context. The working models that people hold in regard to themselves and towards the behaviour of others, working models which may involve the internalisation of significant figures from the past (most typically the parents), are likely to have a powerful bearing on relationships formed in adulthood (Sarason, Sarason and Gurung, 1997). The complexity of measuring the nature of early attachments, as well as simultaneously tracking communication variables within a current attachment or relationship coping with a profound threat such as cancer, is not to be underestimated. However, progress in the understanding of gender differences in the provision of care and support is most likely to be derived from testable hypotheses drawn from developmental theories such as attachment theory.

The fact that the video intervention evaluated in this study had such limited effects may not be surprising in view of the limitations listed above. However, there were sufficient trends in the data (and the lack of contradictory trends) to
retain some optimism about the intervention. The video was largely well received and endorsed by the couples who saw it, and no one complained that it had been actively unhelpful. Indeed, it may be that a more effective film could be made through a revision and expansion of the existing video, in accordance with the points made above. Equally importantly, it is more likely that the effectiveness of the video would be demonstrated if it were evaluated using a considerably larger sample, selected younger couples whose relationships warrant it, or as an adjunct to face-to-face therapeutic work with couples.

The choice of a video intervention was driven by the high incidence of psychological problems among patients and partners affected by cancer, and the need for a cost-effective intervention to help prevent such problems. The fact that this particular intervention appeared to lack therapeutic power is not an argument against the use of the medium of video. There is no published account of a similar intervention. Due to their complexity, human adult relationships may be an over-ambitious target for a video intervention, and more success using this medium may be derived from tackling more discrete problems associated with cancer (e.g. coping with the fatigue caused by radiotherapy, or nausea in chemotherapy).

Whatever the chances of successfully deploying a video intervention to prevent the psychosocial problems associated with cancer, they are likely to be enhanced by ensuring that the process of making the intervention is not simply drawn from the theoretical and empirical work of professionals, but is also intimately informed by the day-to-day experiences of people with cancer and their loved ones.
5. REFERENCES


Adjustment among husbands of women with breast cancer. *Journal of Psychosocial Oncology*, 14, 41-69


6. APPENDICES

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Appendix A1: Final Edit List of the Video Intervention
**FACING IT TOGETHER – On-line Cut-list**

**Music fades in as title appears:** “Facing it Together” (Music Track [Balakirev] 7; 1:32)

**Voice-over:**
For most people, the diagnosis of cancer is a time of enormous stress and anxiety. It is a time when many people feel as if the world has been turned upside-down and nothing seems the same as it was before. As well as having to face the diagnosis, you are having to cope with a medical treatment which may take several months to complete.

And, of course, any serious illness doesn’t simply affect the patient alone; everyone who is close to the patient, especially the patient’s partner, also experiences a lot of worry and distress. The danger here is that this stress can lead to the more serious problems of anxiety and depression.

The aim of this short video is to suggest some steps you might take, as a couple, to help you cope with the months ahead and prevent these problems from developing. It is important to stress that there is no one right way to cope and the most important thing is for both of you to do what you feel is right for your relationship.

Throughout this short video we will be using the term “partner” to refer to the patient’s husband, wife or life-companion.

All of the people who have kindly agreed to speak in this programme have had cancer and received treatment for it at the Bristol Oncology Centre. This is an opportunity for them to tell you about the support they received; you may feel that some of what they say is relevant to your own situation.

**Cut-away:** Couple walking in park under trees (James’s shot)

**Title fades in:** “Facing it together”

**Music fades out as voice over begins**

**Dissolve to Cut-aways:**
1. Suspension bridge 41.24.16 – 41.36.08 (T2)
2. Dissolve to woman on bench 40.27.08 – 40.31.15 (T2)
3. Dissolve to BOC sign 7.29.12 – 7.32.06 (T3)
4. Diss to BOC outside with couple 7.04.01 – 7.12 (T3)
5. Hospital door opens 45.11 – 45.15 (T2)
6. Nurse walking TC 45.44 – 45.46 (T2)
7. Nurse thru door (hand-held) 45.28 – 45.36 (T2)
8. Mark and Anna sitting on bench 11.14 – 11.22 (T2)
9. Mark and Anna walk AFC 12.28 – 12.43 (T2)

**Dissolve to**

Slow zoom into window of house, as we hear Lucy’s voice. 32.51 – 32.56 (T2)
Lucy: I'm thinking back to the time when I walked into that room and the doctor was sitting there, I remember the fact that I had my husband with me and obviously I needed somebody with me because of how frightened I was. I can remember the doctor eventually getting round to the point that I had cancer and completely being overwhelmed by that and I can remember desperately needing my husband to just acknowledge that, just to look at me, just to say something himself.

Chris: When I was first diagnosed with cancer it was horrible. I just wanted the ground to open up and swallow me so that I wouldn't have to deal with it or think about it. I didn't know what to do. I think I was in shock for quite a while. My partner responded by not being able to talk to me about it. I am sure that he was as shocked as I was and upset too, but he didn't want to talk to me and he withdrew, really because he didn't know what to say.

James: Of course the diagnosis of cancer and the treatment which follows is a very stressful time both for the patient and their families, and especially their partner. It's a time of a great deal of uncertainty and many new experiences, so really it's little wonder that a number of people develop emotional problems such as anxiety and depression. The point is that it enormous stress for both the patient and the partner. Now there is some good research to show that people are less likely to develop these kind of problems if the couple are able to support one another and face it together.

Sarah: I started to feel a bit let down by my partner and instead of going to him first and then going to a friend if he couldn't help, I'd go to the friend first so that it has ended up really with us being quite separate and I do feel quite alone. Consequently quite recently I have been quite depressed with this feeling of not being in contact with my partner throughout the experience.
David
After diagnosis we were facing uncertainty, confusion and a lot of fear and the way we looked at it was "We have a problem now, how do we solve it?" So we talked to the experts and we also talked to each other an awful lot. I found I could talk to her about anything and that helped, be it the mundane things or the routine things in life or this afternoon or the treatment coming up. I was surprised how dependent I became upon her and no matter how often she came I still wanted her to be at the hospital with me longer but essentially I discovered that she was the reason I could face every day.

James
I think it's important to stress that there is no one right way of giving support. I think often in these situations we don't really know what to say and we don't know what the best way of supporting somebody and we are often afraid of making the situation worse. I think the most important thing is that the couple are able to continue to talk to one another and support each other in whatever way they can.

Lucy
I mean obviously it was a shock to him, he told me afterwards that he never thought that I did have cancer, he always felt that I wasn't going to have it but he seemed to shut down straightaway then and didn't reach out to me, I needed him to reach out to me, I needed him to hug me, I needed him to hold me, hold my hand, tell me it's OK I'll be there for you, (we'll get through this)

Sarah
I was very frightened and I stayed in that sort of panicky state for quite a long time and what I felt I really needed was for someone to hold me and I needed a lot of hugs really. I really felt that throughout the operation and also when I had my treatment afterwards and even now I feel that if somebody was to hug me for a week it wouldn't be long enough and I find it quite difficult to ask for that sort of affection and caring from my partner.

Caption: "David"

Cut to David

Cut to James

Cut to Lucy

Cut to Sarah

Caption: "Sarah"
People often worry that they may say the wrong thing and make the situation worse. But often it's not a question of finding a solution or giving advice. What's more important is to keep listening and finding out what your partner is feeling and needing at any particular time. And this doesn't always have to involve words...

...And I don't think Fred knew how I was feeling and I couldn't tell him, but, at the same time, he was there, and he listened to me and all I wanted to do when I first came away from the diagnosis was just to go and sit. It was a horrible day, but I just wanted to sit in the car somewhere that didn't bear any relation, I didn't want to go home, I wanted to be somewhere neutral, and he listened to that and he drove the car where I wanted to go and he just sat there and held me and listened and hugged me, words weren't that important at the time.

I think later on it was important to deal with silences. It was better for him to say something, even if it wasn't right, it was better that he responded to what I had said or what I was feeling, rather than not say anything at all. I know sometimes he said he was worried about not saying the right thing, but that didn't matter. It was far easier to deal with him saying the wrong thing and being able to say well, no that's not what I mean, rather than him not saying anything at all, and me sitting there thinking what is going on in there, what do you feel?

I think it's very difficult for the partner because men and women often feel very helpless; they don't know what to do and what to say and they feel awkward and they end up saying nothing sometimes and worse still they might withdraw. But
it's hard for both of them and I think it's important to stress that. If we look at
the partner for a moment; I remember seeing a couple once whereby they were
really struggling because the woman had cancer. It was interesting because he
felt quite rejected by her even though he was trying to support her.

It was clear that as soon as she was diagnosed with cancer she cut off the
support that she would normally give him because she became naturally
preoccupied with her own cancer. But as a result of feeling unsupported by
her, he started being quite critical towards her and she felt quite angry in
return so their relationship began to break down as a result.

So I think it's really important that the partner feels that they can get some
extra support and so that they are able to support the patient better.

Chris: Increasingly he found it harder and harder to talk to me so he would go out
more often or would arrange activities that I couldn't be part of or he didn't
want me to be part of, so we spent more and more time apart and
communicated less and less. He didn't have anybody to talk to other than me so
he couldn't confide in anyone how he was feeling and he couldn't talk to me so
he probably felt very lonely and isolated as I did.

David: It was very important for my wife to have someone she could talk to as well
because she was finding the whole experience stressful. She had to run the
house and go to work and do all the mundane things and still look after this
poor patient who needed all the help he could possibly get. Fortunately she had
a lot of support from friends and immediate family who she could talk to.

VOICE It's easy for the partner to make the mistake that they should be positive
all the time. Of course, it's important to focus on the positive aspects of

Cut-away (at 15.56.12): (T3)
2. Couple on Causeway 36.41.22 – 36.46.02
3. Silhouette of woman 38.23.11 – 38.29.15

Cut-away: (T2)
Two women walking AFC in park
37.19.00 – 37.26.05

Cut-away: (T3)
Man (David) on doorstep 20.54.12 – 21.00.00
the situation, but it's also vital that the patient has the opportunity to talk about anything that's on their minds no matter what it is. By encouraging people only to talk about positive things, we discourage them from telling us what they are really feeling.

Chris  He was worried that he would say the wrong thing some of the time so he thought it was easier to say nothing I think. I wanted to talk to him about the possibility of me not getting better and what would happen, what would be the future for the children, but he didn't want to talk about that. I was only allowed to talk to him if I was going to say positive things about getting better, and not to talk about anything else.

Sarah  As time went on I started to worry about the cancer spreading, as I am sure everybody does, and I'd get odd aches and pains and things, perhaps I'd have a pain in my leg all day and I'd be so worried about it and there was no one I could talk to and whereas my partner was strong when I used to talk to talk to him about such aches and pains, his reaction was more don't be silly, it's quite all right. I actually needed someone to say well that must be very scary to feel like that and to understand what a bad day I'd had...

James  || I think when we've been part of a couple for some time, one of the problems is that we tend to assume we know what our partners are thinking about and consequently we end up interrupting them quite a bit. The trouble is that when we interrupt people we obviously stop listening to them and tend to shut them up and we never get to hear what it is they actually wanted to tell us. So that's a problem.

Cut-aways:
1. Couple walking AFC in park (T3) 43.54.17 – 43.59.06 Dissolve to
2. Family picnic (T2) 42.31.19 – 42.38.03 dissolve to
3. Couple on bench from back (T3) 40.59.06 - 41.03.16 dissolve to
4. Two men walking TC (T3) 42.38.12 – 43.45.20

Cut to James
our partners what it is that we do want to say and what it is that we are feeling, and sometimes because we are afraid of being disappointed.

I have to be quite clear about what I need and I think he does respond if I am clear about what I need and I suppose in that sense the onus is on me to be aware of myself and maybe that is a lesson that I've learnt myself

When he got over the shock and when I'd got over the shock I really wanted to talk about it but I became really very, very low and I think the problem when you are low is that you, well I felt afraid to actually say how I felt because I didn't know what the reaction would be and sometimes I know I would give the impression that I didn't actually need him and I would maybe give the impression that I didn't want him to touch me or I didn't want him to talk about it but really I actually wanted the opposite, I actually wanted him to be close and hold me and make me feel like a person still and not like somebody that was somehow marked || now that I had cancer.

Fade to dark green

(Voice over with “glowing” captions on dark green)

“We'd now like to summarise the main points of this video... (approx 1:15)

1. Anxiety and depression are less likely to develop if the couple are able to face the stress of cancer together

2. Try to be clear with each other about what you are feeling, but don’t assume you know what your partner is feeling or thinking

3. Do your best not to interrupt your partner when they are speaking; try to listen more than talk
4. Avoid being critical of your partner; remember that it is a stressful time for both of you and that both of you need support.

5. Words may not always be as important as giving or receiving a hug from your partner.

6. Remember that being overly positive, giving advice or finding a solution is not always what’s needed; try to find out instead whatever your partner would find it helpful to talk about.

7. Don’t worry about saying the wrong thing — the important thing is to try to stay involved.

8. And finally, find someone else you can talk to, and get support from, on a regular basis.

Voice-over: Of course many couples confront the crisis of cancer by facing it together and as a result they feel very well supported. It is wise though for both the patient and their partner to have someone else outside their relationship to talk to as well and get as much support from other people as they can. After all, for any of us, the better supported we feel the more able we are to give our partners support. No one should have to face their treatment on their own. It just makes such a difference if the couple are able to face it together.

Cut-aways: Couple emerge thru door 3.53.12 – 4.06.19 (T3)
Couple from back 04.26.00 – 04.28.08 (T3)
Couple go past camera 05.05.06 – 5.11.07 (T3)
Dissolve to “magic tree” as music fades in (from CD 1:32) and credits appear 43.33.18 – 43.48.20 (T3)

"Our sincere thanks to Bette, Lucy, Chris, Sue, Anula, Sarah and David for their kind help in making this video, and for the work and generosity of Richard Maxwell (Soft Focus Films)"

Captions and voice-over simultaneously?
As soon as the video has ended, please each open one of the envelopes that came with the video and separately complete the questionnaire, without discussing your responses with one another until you have sealed them in the envelope provided. This is very important to the research we are conducting.

Please post these envelopes within the next 24 hours. Please also read the leaflet now and keep it safe.

We hope you have found the video useful and that you will do your best to put the advice into practice.
Appendix B: Local Research Ethics Committee Approval
Dear Mr Brennan

E3780  **An evaluation of two preventive psychosocial videos**

Following viewing of the three videos by Dr. A Preece, I am pleased to advise that approval has been given as detailed below:

Approval under Category D and with a signed release form for that part of the study which makes a video of the research subjects.

Approval under Category C for that part of the study which sends a video already made to subjects who are not included in the video.

The Committee requires you to complete the attached end of study summary/yearly report at the appropriate time and return it to this office.

Yours sincerely

Naaz Nathoo
Secretary to the Research Ethics Committee
Dear Mr Brennan

BA66/97-98
An evaluation of two preventive psychosocial videos (in patients and their partners with colorectal cancer)

This application, which included the documents listed below, was considered at the Bath Research Ethics meeting on 25 September 1997.

- application form
- protocol
- patient consent form
- questionnaire

This study was approved by the Committee, and may now proceed.

Any changes or extensions to the protocol, or additional investigators should be notified to the Committee for approval. Adverse events should also be notified to the meeting. May we remind you of the Data Protection Act 1984 and the need to conduct the trial in accordance with the Good Clinical Practice Guidelines.

The Committee is required to audit progress of research and to produce a yearly report to the Avon Health Authority and Department of Health. You are therefore required to provide a brief yearly report and a short final report.

Yours sincerely

Dr J P D Reckless
Chairman
Dear Mr Brennan

An Evaluation of Two Psychosocial Videos

At the meeting of the West Somerset Ethics Committee held on 11 November 1997, members considered the above study which was deferred from the previous meeting pending a report from one of our Consultant Clinical Psychologists.

Members concluded that all the concerns previously raised were satisfactorily addressed, however it was considered that the patient consent form should be amended to make it clear that any participant in the study who may caused distress by the questionnaire or video will be able to see and discuss the matter with either yourself or their consultant oncologist.

Subject to this amendment, approval was granted. The Committee look forward to receiving an update in six months time.

Yours sincerely

D N CHALLACOMBE MD FRCP
Chairman
West Somerset Ethics Committee
Dear Mr Brennan

RE: EC027/97 - AN EVALUATION OF TWO PSYCHOSOCIAL VIDEOS

I can now confirm the Committee’s approval to this study which is subject to the following conditions:

1. The Committee will be informed of any adverse effects on any patient.

2. A copy of any publication as a result of the study is passed to the Committee.

3. A summary of the progress of this study to be received by 30th September, 1998 for inclusion in the East Somerset Committee Report to the Somerset Health Commission.

We wish you luck with this study.

Yours sincerely

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DR JANE BALDWIN
CHAIRMAN LOCAL RESEARCH ETHICS COMMITTEE
Appendix C: Consent Forms and Letters to Subjects

- Consent information for patients taking part in the video: page 213
- Consent form for patients taking part in the video: page 214
- Release form for patients taking part in the video: page 215
- Letter inviting subjects to participate in the study: page 216
- Consent information and Consent Form for subjects: page 218
- Letter accompanying first questionnaires: page 221
- Letter accompanying video: page 222
- Letter to control subjects: page 223
- Letter accompanying second questionnaires: page 224
- Thank you letter: page 225
An Invitation to Participate in the Production of Prevention Videos

Introduction: You are invited to take part in a short video that will be used in a research study to examine the effectiveness of providing psychological information to patients recently diagnosed with cancer. Please read through this sheet which explains why we want to do this research and what it would mean for you if you decide to take part.

The reason why the research is being done: There is an increasing interest in and demand for psychological and social support in hospital cancer care services. It is therefore important that research is done to see which forms of care are effective. To achieve this we need to compare people who are given a new information video with those who are not, but who are otherwise being cared for in the same way.

What taking part in the video would be like for you: If you agree to take part in the video, you will be asked to spend one day in Bristol during which we will film you and obtain your ideas about the whole project. We will be making two separate videos though it will be up to you to decide which of them you would like to contribute to. Video 1 will be concerned with the extent to which you managed to stay involved with normal activities in your life while undergoing treatment. Video 2 is concerned with how much support you felt you received from your partner following diagnosis and during treatment. In the morning we will discuss what aspects of your personal experiences will be most relevant to our particular area of interest. The video recordings will take place in the afternoon. It is important to stress that you are at liberty to say only what you feel comfortable saying on camera and we would encourage you not to disclose deeply personal or any identifying material. Any names you may wish to use (for example, your partner's first name if you feel it would be natural to use a name) should be disguised. A cameraman & and a female camera assistant will be present along with Lunch will be provided.

Use of the Video: You will be shown the edited video, and only if you are happy with the content, will it be used in the research. If you agree to its use, we will then ask you to sign a release form (a copy is attached). The release form will permit us to distribute the completed video to the patients involved in the research. Should the research provide good results we may also wish to present the video to others. The release form would give us permission to use the video in the future without seeking any further consent.

Voluntary participation: We want to make it very clear that we do not want you to feel under any pressure at all to participate in this research. Whether or not you take part will in no way affect any future care you may receive at the Bristol Oncology Centre.

Further information: Should you want any more information before making your mind up, then telephone and, if no one replies, leave a message on the answer machine, along with a time that would be convenient for us to get back to you.

Complaints or comments: If you are unhappy about the way in which this project has been introduced to you or carried out, then please contact UBHT Research Ethics Committee.

Thank you very much for your help.

Kind Regards

Trainee Clinical Psychologist

Consultant Clinical Psychologist
Consent Form

Study Titles: ‘A Research Project on the Effectiveness of a Video Information Package’
‘An Evaluation of Two Preventive Psychosocial Videos’

Please complete the following questions:

Have you read this information sheet? Yes / No

Do you feel that you have enough information about what will be asked of you
and how the video will be used? Yes / No

Do you understand that you are free to withdraw from the project:

- At any point, prior to having seen the completed video and signed
  the ‘Release’ form.
- Without having to give a reason for withdrawing
- And without affecting your future medical care Yes / No

Do you agree to take part in the video? Yes / No

Signed ................................................................. Date ...........................................

(Name in block letters) ....................................................................................................
Release Form

Study Titles: ‘A Research Project on the Effectiveness of a Video Information Package’
‘An Evaluation of Two Preventive Psychosocial Videos’

Having consented to being filmed as part of the above study and having viewed the completed video, I am happy to give my permission for either James Brennan or Mark Barrington to use the video in whole or part, at any point in the future for research, clinical or teaching purposes, without having to seek further consent from me. I understand that at no point will my name be revealed or any personal or identifying details about me or my family.

I agree with this statement

Yes / No

Signed ................................................................ Date...........................................

(Name in block letters) .........................................................................................
Dear Mr and Mrs

Thank you so much for agreeing to hear more about our research. As a result of your kind support we hope that we can improve the care given to new patients and their partners. I realise that this may be quite a stressful time for you both and I certainly have no wish to give you anything else to worry about. However, this research (which is fully supported by your oncologist) only involves filling out questionnaires in your own home (i.e. no contact with anyone else), and most people so far have found it quite interesting.

There are three stages to this research which is all about how couples cope when one of them has been diagnosed with cancer. The enclosed Consent Form goes into more detail about what the research will involve but here is a simple summary:

**Stage 1**
After we have received the enclosed Consent Form (which must be signed by both of you) you will each be sent a different questionnaire, depending on whether you are the patient or the “partner” (husband, wife or life-companion). This takes about 40 minutes to complete if you are the patient and about 20 minutes if you are the partner.

**Stage 2**
As soon as we get the questionnaires back from you, you will be randomly put into one of two groups; this is like drawing names out of a hat – neither you nor I will have any control over which group you go into. One group of couples will receive (in the post) a video, and the other group will not. For the research to be effective this process of putting people into groups has to be completely random. If you are in the group receiving the video (which is about 15 minutes long and entirely free), it will be sent to you in the post with a short leaflet for you to keep and another very short questionnaire to complete. If you are in the group that does not receive a video I will let you know by sending you a short note.
Stage 3
Finally, three months later, we will ask you to complete most of the first questionnaires again. It will be very important to us if, having completed stages 1 and 2, you could complete stage 3 because without it we will not be able to use your data.

* * *

It is important to stress that all the research will be done by post. You will not have to come into the hospital because of the research, and the research will not affect your treatment in any way at all and everything you write on the questionnaires will be seen only by me and my research assistant. We will provide you with stamped addressed envelopes in which to return all the questionnaires, and you will be welcome to keep the video or return it to us if you prefer.

At this stage I would be grateful if you would read the enclosed Consent Form and return it to me in the envelope provided and, if possible, within the next two days.

Please return this slip on the Consent Form whether or not you wish to participate in our research!

Many thanks.

With Best Wishes

Yours Sincerely

[Signature]

Consultant Clinical Psychologist
Research Consent Form
The Evaluation of a Psychosocial Video

You are invited as a couple to take part in a research project to find out the effect of a video on how couples cope with the stress of one of them having cancer. Please read through these notes which will explain why we are doing this research and what, in practice, it would mean to you if you took part.

The reason why the research is being done
There is increasing interest in and demand for psychological and social support for people who are being treated for cancer. It is therefore important that research is done to see which forms of care are the most effective and, in particular, the best methods of preventing psychological problems from developing. To achieve this, we want to evaluate a video to see if it is effective in helping couples cope with their situation, and thereby prevent later problems. We also need to compare the couples receiving videos with couples who receive routine care and do not see the video.

What taking part in the research would be like for you
The research is concerned with how both members of a couple cope when one of them has been diagnosed with cancer. Therefore, if you agree to take part we will need to collect information from both of you. We will send each of you a questionnaire which you will be asked to complete without discussing your answers with each other. The questionnaires will be sent to you with a stamped addressed envelope for you to return them in.

Once we have these questionnaires back, you will either be sent the video or a note saying that you will not be receiving one. Half of all couples will receive a video and half of couples will not. Whether or not you get the video will be decided purely by a random process, like pulling names out of a hat. You will be free to keep the video if you receive one. Finally, three months later, when most or all of the treatment will probably be over, you will both be asked to complete most of the questionnaires (again separately of one another), whether or not you actually received a video Once again they will be sent to you with a stamped addressed envelope for you to return them in.

These questionnaires take roughly 40 minutes to complete (though the questionnaires for the patient’s partner are much shorter). The video takes about fifteen minutes to watch and will require you to watch it together as a couple.

Confidentiality
All your answers are confidential and all the research will be conducted by post so you will not be required to see anyone to do with the research. The questionnaires will not have your names on them, only a code number, and they will be kept locked away. The questionnaires will be seen only by the researcher and his assistant, and not even your partner will be able to see what you have written! At no point will your name or participation be revealed.

Voluntary Participation
Please understand that we do not want you to feel under any pressure at all to participate in this research. Whether you take part will not way affect the care you
receive at the Bristol Oncology Centre. If you do agree to participate you are free to change your mind and withdraw from the research project later.

**Further Information**
If you have any concerns or questions about this research project, or if any aspect of it causes you distress, you are welcome to contact me, in writing or by phone, at the following address: [Name] Consultant Clinical Psychologist, Bristol Oncology Centre, Horfield Road, Bristol BS2 8ED (Tel: [Phone number]). Alternatively, you may contact your consultant oncologist.

**Complaints or comments**
If you are unhappy about the way in which this research has been introduced to you or carried out, then please contact the UBHT Ethics Committee: [Name] Secretary, Research Ethics Committee, Trust Headquarters, Marlborough Street, Bristol BS1 3NU (Tel: [Phone number]).

**To summarise:** The study is done entirely by post and will require no extra trips to the hospital; nor will you be required to meet anyone to do with the research. It will not affect your treatment in any way. Your answers on the questionnaires will be kept completely confidential and will not be revealed to anyone.

*We would be enormously grateful if you felt able to help us with our research.*

Yours Sincerely

[Name]
Consultant Clinical Psychologist

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**CONSENT FORM**

**Study Title:** *The Evaluation of a Psychosocial Video*

Please complete the following questions:

Please cross out as necessary

- Do you feel you have understood the information on this sheet? YES / NO
- Do you feel you have received adequate information about this study? YES / NO
- Do you both agree to take part in this study? YES / NO

Signed (by both of you): ........................................... ...........................................

Date: ....................

Names in Block letters: ........................................... ...........................................
Please keep these details about the study but return this tear-off slip in the envelope provided to:

Bristol Oncology Centre, Horfield Road, Bristol BS2 8ED
PLEASE READ THIS FIRST!

Dear Mr and Mrs

Thank you so much for agreeing to participate in our research. With your help, we hope that our research will lead to improvements in care to patients and their partners all over the country. We are therefore very grateful for your help.

You will find enclosed two envelopes, marked Patient and Partner. Please take the one that is for you and complete it alone. It is very important to the research that neither of you receive help or advice from your partner when you complete these questionnaires. Therefore it’s best to complete the questionnaires and seal them in the envelopes in separate rooms if possible! Some of the questions are quite personal but please remember that no one will be able to identify your questionnaire because it has a code that only I can interpret.

Please seal and return the questionnaires in the envelopes they came in within the next three days. As soon as we have them back you will be assigned (randomly) to one of two groups. One of these groups will receive a free video and the other group will not. I will write back to you within a week of getting these questionnaires to let you know the outcome.

Thank you again for your help. I look forward to getting your questionnaires back as soon as possible. (Please try to post them back to me within the next three days, if at all possible).

With Best Wishes

Yours Sincerely

Consultant Clinical Psychologist
Dear

Thank you for returning the questionnaires. I hope they weren’t too tiring to complete.

As you can see, you have been assigned to the group which receives the video. This video is designed to help you cope, as a couple, with the stress of the medical treatment you are undergoing; I hope you find it helpful. Along with the video are two leaflets which should be read after you have watched the video together.

It is important to the research that you both watch the video and do so together but without others present. Try to find a quiet time. Please also both complete the short questionnaires that are in the enclosed envelopes but, like the previous questionnaires, please complete these separately. Then please return them to me in separate envelopes without looking at your partner’s responses.

Again, I would be grateful if you would return these short questionnaires as soon as possible (within the next three days).

The next and final stage of the research will be when I contact you again in about three months time, with most of the questionnaires you recently completed. It will be vital to the research that you are able to complete these last questionnaires, so we really do value your continued participation in this important research.

Thank you again very much for your help.

With Best Wishes

Yours Sincerely

[Signature]

Consultant Clinical Psychologist
Dear Mr and Mrs,

Thank you so much for returning the questionnaires. I hope they weren’t too tiring to complete.

You were randomly assigned to the group which does not receive a video. Although you may find this a bit disappointing, it is important to stress that your input into this research is still extremely important. In order for us to evaluate the effects of the video we need to compare the couples who watch it with couples who do not. Therefore, without your participation the research would have no value.

The next and final stage of the research will be when I contact you again in about three months, with most of the questionnaires you recently completed. It will be vital to the research that you are able to complete these last questionnaires, so I really do value your continued participation in this important research.

Thank you again so much for your help.

With Best Wishes

Yours Sincerely

[Signature]

Consultant Clinical Psychologist
Dear Mr and Mrs

I do hope you remember this research project we are conducting. This is the last but also the most important stage of the research, so we very much value your continued help. All of your valuable input so far can only be used once we get back the enclosed questionnaires, so I cannot stress enough the importance of these last questionnaires to this study.

To remind you of the procedure, you will find two envelopes enclosed, marked Patient and Partner. Please take the one that is for you and complete it alone. It is very important to the research that neither of you receive help nor advice from your partner when you complete these questionnaires. Therefore it’s best to complete them in separate rooms if possible. Some of the questions are quite personal but please remember that no one will be able to identify your questionnaire because it has a code that only I can interpret.

Please seal and return the questionnaires in the envelopes that they came in within the next three days if at all possible.

Finally, I am enormously grateful to you both for your help with this research project. I realise that I have asked you to complete a lot of questionnaires at a time which has probably been very stressful. I sincerely hope that your help with this project will lead to improved care for other couples facing the kind of stress you have coped with over the past few months.

Thank you again.

With Best Wishes

Yours Sincerely

[Signature]

Consultant Clinical Psychologist
Dear Mr and Mrs

This is just a short note to thank you so much for taking the trouble to complete all the questionnaires I sent you. Conducting research in this area is delicate and time-consuming, as I am sure you can appreciate, and it is not easy to find couples who are kind enough to spare their time in the way that you have. So I am enormously grateful.

Thank you again for your generous help.

With Best Wishes

Yours Sincerely

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Consultant Clinical Psychologist
Appendix D: Research Questionnaires
This form is for the person who is the patient

Research Questionnaire

The Evaluation of a Psychosocial Video

Thank you so much for agreeing to take part in this research. As a result of your help we hope that this research will lead to other people receiving better care in the future.

Please complete every item in this questionnaire. Read carefully the instructions for each section and, after you have finished, check that all questions have been answered.

Please find somewhere on your own to complete the questionnaire. As soon as you have finished, seal it in one of the envelopes provided and try to post it within 3 days of the day you received it.

IMPORTANT

For this research to be successful, it is extremely important that you complete all the questions on your own. In other words, without anyone helping you or influencing what you write.

Please do not help, or receive help from, your partner.

Remember: the term “your partner” in this questionnaire refers to the person you are married to, or living with.

Some of the questions may seem quite personal but please try to be as honest as you can possibly be. Remember that your answers will be kept entirely confidential and, as you can see, this form contains a code (i.e. not your name) which only the researcher understands.

Your details will not be revealed to anyone else.

Thank you again very much for helping with this research.
1. **DEMOGRAPHIC QUESTIONS** *(Please answer ALL the questions)*

1. Are you the **patient** ☐ or the **partner of the patient** ☐ *(tick one box)*

2. Are you Male ☐ or Female ☐ *(tick one box)*

3. Please state your age ____________________________

4. If you have children, please state their sex and age
   *(for example: girl of 21, boy of 18, etc.)*
   ________________  ________________

5. Please circle any children currently living with you at home

6. How many years have you been living with your partner? __________ years

7. Are you married ☐ or “living together” ☐ *(tick one box)*

8. Have you been previously married (or in an equivalent long-term relationship)? YES ☐ NO ☐

9. Who is the major wage earner in your present relationship? Me ☐ My Partner ☐

10. What is the occupation of the major wage earner? ____________________________

11. *(a)* Are you currently in work Full-time ☐ I don’t work ☐ *(tick one box)*
    Part-time ☐ Unemployed ☐
    Voluntary work ☐ Retired ☐

    *(b)* If you are in work, have you had to reduce the amount you work because of the illness?
    YES ☐ NO ☐

12. At what age did you leave full-time education? __________

13. At what point did your education finish? During:
   Secondary school ☐
   College/technical college ☐
   University/Polytechnic ☐

14. Have you ever received any psychiatric or psychological treatment? YES ☐ NO ☐
    If so, please briefly state what the treatment was for:
    ____________________________

15. Are you currently receiving any medication for
    anxiety ☐ none ☐ *
    depression ☐
    other psychiatric condition ☐ ________________

16. Are you currently receiving any formal support *(e.g. counselling, therapist, self-help group)*? YES ☐ NO ☐
    If so, please specify
    ____________________________
17. **Looking back on your life, have you had to cope with any of the following?**

(a) A brother, sister, parent or child of yours being diagnosed with cancer? 

| YES ☐ | NO ☐ |

If yes, please specify, with year & illness

(b) Receiving a diagnosis of cancer yourself? 

| YES ☐ | NO ☐ |

If yes, please specify year & diagnosis

(c) Receiving the diagnosis of a potentially life-threatening disease yourself? 

| YES ☐ | NO ☐ |

If yes, please specify year & diagnosis

(d) A period of more than one month when you have been seriously ill? 

| YES ☐ | NO ☐ |

If yes, please specify year & diagnosis

(e) A period of more than two weeks when you single-handedly had to look after someone else who was ill or very dependent? 

| YES ☐ | NO ☐ |

If yes, for how long?

(f) A period of more than two weeks when you were separated from both your parents before you were four years old? 

| YES ☐ | NO ☐ |

(g) A period of depression which interfered with your life (whether or not you were given treatment for it) 

| YES ☐ | NO ☐ |

(h) A period of stress or anxiety which interfered with your life (whether or not you were given treatment for it) 

| YES ☐ | NO ☐ |

18. **Have you had any other major stresses to cope with over the past six months?** 

| YES ☐ | NO ☐ |

If yes, please specify

19. **When you are completely honest with yourself, who has been your most important* source of support since you learned that you had cancer?**

| My partner ☐ | My daughter ☐ | My sister ☐ |

| My mother ☐ | My son ☐ | A male friend ☐ |

| My father ☐ | My brother ☐ | A female friend ☐ |

* (Tick one box only)

Other *(please specify relationship to you)* ☐ 

Sex of this person: ☐
20. How many weeks is it since you were diagnosed with cancer? [ ] weeks

Please tick the box if you are receiving any of the following treatments or have received them over the past two months

- Surgery □
- Radiotherapy □
- Chemotherapy □
- Hormone treatment □

(Tick whichever boxes apply)

2. CONCERNS

1. We are interested in learning about the kinds of concerns and worries that people have about their cancer and its treatment. Here is a list of concerns and worries. Please state how concerned you have been about each of these over the past month, using the following answers:

   Put the number in the boxes below which best describes what you have felt

   0 I have not been at all concerned about this
   1 I've been a little concerned about this
   2 I've been moderately concerned about this
   3 I've been considerably concerned about this
   4 I've been extremely concerned about this

   a) Physical problems or discomfort due to the treatment
   b) Feeling that I'm less desirable or acceptable to my partner (or to a potential partner)
   c) The effect of my illness on people close to me
   d) Uncertainty about whether the cancer will recur or spread in the future
   e) Other (please specify) ........................................

   (Put a number in every box)

2. Which one of these have you been most concerned about? (a, b, c, d, or e)

   (choose one only)
3. Now please go through the same list of concerns, and consider how much you have talked about each of these with your partner.

*Please use the following answers by putting the appropriate number in the boxes below*

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Talked about none of what I felt</td>
</tr>
<tr>
<td>1</td>
<td>Talked about a bit of what I felt</td>
</tr>
<tr>
<td>2</td>
<td>Talked about some of what I felt</td>
</tr>
<tr>
<td>3</td>
<td>Talked about much of what I felt</td>
</tr>
<tr>
<td>4</td>
<td>Talked about all of what I felt</td>
</tr>
<tr>
<td>5</td>
<td>Haven't had this concern</td>
</tr>
</tbody>
</table>

(a. Physical problems or discomfort due to the treatment)
(b. Feeling that I'm less desirable or acceptable to my partner (or potential partner))
(c. The effect of my illness on people close to me)
(d. Uncertainty about whether the cancer will recur or spread in the future)
(e. Other (please specify))

4. Here is a list of different feelings you may have had since your illness. Please say how much you have talked about each of these feelings with your partner, using the same answers:

Times when I've felt:
(a. tense, nervous, uneasy, or anxious)
(b. sad, discouraged, gloomy, or downhearted)
(c. angry, bad-tempered, furious, or annoyed)
(d. positive, hopeful and more cheerful)

5. How helpful or unhelpful, to you has it been when you've talked about these concerns and feelings with your partner?

- Very unhelpful
- Moderately unhelpful
- Slightly unhelpful
- Slightly helpful
- Moderately helpful
- Very helpful

(Tick one box only)
6. When you have talked about your concerns and feelings with your partner it may have had different kinds of results. Here is a list of things people may feel after they've talked. Please say how much each one is true or untrue for you, using the following answers:

When I've talked with my partner about my concerns and feelings to do with my illness:

a. It gave me a feeling of relief or reassurance
b. It made me feel more confused or less clear about things
   (Put a number in every box)
c. It helped me think about things I could do to feel better
d. It made me dwell more on my concerns and feelings
e. It helped me see things differently, more clearly, or in a different light
f. It made me feel worse, more worried or upset
g. It helped me get things off my mind
h. It left me thinking that there was nothing I could do to feel better

7. Ideally, how much would you like to have talked about your concerns and feelings with your partner? Would you like to have talked less, more or have you talked as much as you would like to have done?

I would like to have talked:

a. a lot less about what I felt
b. a bit less about what I felt
   (Tick one box only)
c. I've talked about as much as I want to
d. a bit more about what I felt
e. a lot more about what I felt
8. People sometimes say that they hold back from talking about their concerns or feelings to do with their illness, for various reasons. To what extent have you held back from talking to your partner about your concerns or feelings?

0 Not at all
1 A little bit
2 Quite a lot
3 A lot

(Tick one box only)

9. Below is a list of reasons why people may hold back from talking about their concerns or feelings to do with their illness. Please tell me how much each reason is true or untrue for you, using the following answers:

Put the number in the boxes below which best describes what you have felt

1 Strongly true for me
2 Moderately true for me
3 Slightly true for me
4 Slightly untrue for me
5 Moderately untrue for me
6 Strongly untrue for me

I've held back from talking to my partner about my concerns and feelings to do with my illness because:

a. I don't want to worry him/her ____________________________

b. I don't think s/he would understand ________________________

c. I don't want to upset him/her _____________________________

d. S/he doesn't like me to talk about my concerns or feelings

e. S/he doesn't know what to do or say when I'm upset ______

f. I think s/he would gloss over it or make light of it _________

g. S/he wants to hear from me that I'm doing well ________

h. I think s/he would criticize me ____________________________

i. Other (please specify) ..................................................
10. We are interested in how much those close to you understand your experience of having had cancer — that is, how much they understand your feelings, concerns, and what the experience has been like for you. The statements below describe a variety of ways in which people might respond to you.

Consider each statement in terms of how your partner has responded to you since your illness. Please say how much each one is true or untrue for you, using the following answers:

**Put the number in the boxes below which best describes what you have felt**

1. Strongly true for me
2. Moderately true for me
3. Slightly true for me
4. Slightly untrue for me
5. Moderately untrue for me
6. Strongly untrue for me

a. S/he nearly always knows exactly what I mean.

b. S/he may understand my words but s/he does not see the way I feel.

c. S/he usually senses or realises what I am feeling.

d. His/her own attitudes towards some of the things I do or say prevent him/her from understanding me.

e. His/her response to me is usually so fixed and automatic that I don’t really get through to him/her.

f. She/he appreciates exactly how the things I experience feel to me.

g. S/he just takes no notice of some things that I think or feel.

h. S/he does not realise how sensitive I am about some of the things we discuss.

i. S/he understands me.

j. S/he realises what I mean even when I have difficulty in saying it.

(Please put a number in every box)
11. How did your partner react to the news of the cancer?

How did you think the illness or treatment has affected him or her?

12. How stressful do you think it has been for your partner to find out about the cancer?

0 Not at all stressful
1 Slightly stressful
2 Moderately stressful
3 Very stressful
4 Extremely stressful

(Tick one box only)

13. Since the illness, has your relationship with your partner changed at all? Overall, would you say it has got better, worse, or hasn’t changed?

1 A lot worse
2 A bit worse
3 Hasn’t changed
4 A bit better
5 A lot better

(Tick one box only)

In what way?

14. How supportive do you feel your partner has been to you since the illness was diagnosed?

0 Not at all
1 Slightly supportive
2 Moderately supportive
3 Very supportive
4 Extremely supportive

(Tick one box only)
15. How critical towards you has your partner been since the illness?

0 Not at all
1 Slightly critical
2 Moderately critical
3 Very critical
4 Extremely critical

(Tick one box only)

16. How withdrawn from you has your partner been since the illness?

0 Not at all
1 Slightly withdrawn
2 Moderately withdrawn
3 Very withdrawn
4 Extremely withdrawn

(Tick one box only)

17. The dots on the following line represent different degrees of happiness in your relationship with your partner. The middle point, “happy”, represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

Extremely Fairly A little Happy Very Extremely Perfect
Unhappy Unhappy Unhappy Happy Happy

18. Please write the appropriate number beside each question below according to this scale:

5 All of the time
4 Most of the time
3 Often
2 Occasionally
1 Rarely
0 Never

Please complete every question
3. PROBLEMS AND COMPLAINTS

Below is a list of problems and complaints that people sometimes have. For each item, select one of the numbers that best describes HOW MUCH DISCOMFORT THAT PROBLEM CAUSED YOU DURING THE PAST MONTH. Write one number in the space to the right of each problem.

The numbers refer to these phrases:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>A little bit</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Quite a bit</td>
</tr>
<tr>
<td>4</td>
<td>Extremely</td>
</tr>
</tbody>
</table>

**HOW MUCH WERE YOU DISTRESSED BY:**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nervousness or shakiness inside</td>
<td></td>
</tr>
<tr>
<td>2. Loss of sexual interest or pleasure</td>
<td></td>
</tr>
<tr>
<td>3. Feeling easily annoyed or irritated</td>
<td></td>
</tr>
<tr>
<td>4. Feeling low in energy or slowed down</td>
<td></td>
</tr>
<tr>
<td>5. Thoughts of ending your life</td>
<td></td>
</tr>
<tr>
<td>6. Trembling</td>
<td></td>
</tr>
<tr>
<td>7. Crying easily</td>
<td></td>
</tr>
<tr>
<td>8. Feelings of being trapped or caught</td>
<td></td>
</tr>
<tr>
<td>9. Suddenly scared for no reason</td>
<td></td>
</tr>
<tr>
<td>10. Temper outbursts that you could not control</td>
<td></td>
</tr>
<tr>
<td>11. Blaming yourself for things</td>
<td></td>
</tr>
<tr>
<td>12. Feeling lonely</td>
<td></td>
</tr>
<tr>
<td>13. Feeling down</td>
<td></td>
</tr>
<tr>
<td>14. Worrying too much about things</td>
<td></td>
</tr>
<tr>
<td>15. Feeling no interest in things</td>
<td></td>
</tr>
<tr>
<td>16. Feeling fearful</td>
<td></td>
</tr>
<tr>
<td>17. Heart pounding or racing</td>
<td></td>
</tr>
<tr>
<td>18. Feeling hopeless about the future</td>
<td></td>
</tr>
<tr>
<td>19. Feeling tense or keyed up</td>
<td></td>
</tr>
<tr>
<td>20. Having urges to beat, injure or harm someone</td>
<td></td>
</tr>
<tr>
<td>21. Having urges to break or smash things</td>
<td></td>
</tr>
<tr>
<td>22. Feeling everything is an effort</td>
<td></td>
</tr>
<tr>
<td>23. Spells of terror or panic</td>
<td></td>
</tr>
<tr>
<td>24. Getting into frequent arguments</td>
<td></td>
</tr>
<tr>
<td>25. Feeling so restless you couldn’t sit still</td>
<td></td>
</tr>
<tr>
<td>26. Feelings of worthlessness</td>
<td></td>
</tr>
<tr>
<td>27. The feeling that something bad is going to happen to you</td>
<td></td>
</tr>
<tr>
<td>28. Shouting or throwing things</td>
<td></td>
</tr>
<tr>
<td>29. Thoughts and images of a frightening nature</td>
<td></td>
</tr>
</tbody>
</table>

*Please complete every question.*
4. YOUR RELATIONSHIP

Please answer each question below by circling the number which best represents your feelings about your partner. The second part of each question asks you to rate how you would like things to be if they were exactly what you hoped for (your ideal). As before, put a circle around the one number which shows what you feel.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a) Can you trust, talk to frankly, and share your feelings with your partner?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b) What rating would your ideal be?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>2a) Can you lean on and turn to your partner in times of difficulty?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b) What rating would your ideal be?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>3a) Does he/she give you practical help?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b) What rating would your ideal be?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>4a) Can you spend time with him/her socially?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b) What rating would your ideal be?</td>
<td></td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

5. VIEWS ABOUT YOURSELF

Please enter the number of the response that is closest to how you currently feel about yourself regarding each of the following statements.

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel that I am a person of worth, at least on an equal plane with others</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>2</td>
<td>I feel that I have a number of good qualities</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>3</td>
<td>All in all, I am inclined to feel that I am a failure</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>4</td>
<td>I am able to do things as well as most other people</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>5</td>
<td>I feel I do not have much to be proud of</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>6</td>
<td>I take a positive attitude towards myself</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>7</td>
<td>On the whole, I am satisfied with myself</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>8</td>
<td>I wish I could have more respect for myself</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>9</td>
<td>I certainly feel useless at times</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
<tr>
<td>10</td>
<td>At times I think I am no good at all</td>
<td>0 Strongly Disagree, 1 Disagree, 2 Agree, 3 Strongly Agree</td>
</tr>
</tbody>
</table>
Please read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling IN THE PAST WEEK. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. **TICK ONLY ONE BOX IN EACH SECTION**

<table>
<thead>
<tr>
<th>I feel tense or wound up:</th>
<th>I feel as if I am slowed down:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Most of the time</td>
<td>□ Nearly all the time</td>
</tr>
<tr>
<td>□ A lot of the time</td>
<td>□ Very often</td>
</tr>
<tr>
<td>□ From time to time, occasionally</td>
<td>□ Sometimes</td>
</tr>
<tr>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I still enjoy the things I used to enjoy:</th>
<th>I get a sort of frightened feeling like 'butterflies' in the stomach:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Definitely as much</td>
<td>□ Not at all</td>
</tr>
<tr>
<td>□ Not quite as much</td>
<td>□ Occasionally</td>
</tr>
<tr>
<td>□ Only a little</td>
<td>□ Quite often</td>
</tr>
<tr>
<td>□ Hardly at all</td>
<td>□ Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling, as if something awful is about to happen:</th>
<th>I have lost interest in my appearance:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Very definitely and quite badly</td>
<td>□ Definitely</td>
</tr>
<tr>
<td>□ Yes, but not too badly</td>
<td>□ I don't care so much as I should</td>
</tr>
<tr>
<td>□ A little, but it doesn't worry me</td>
<td>□ I may not take quite as much care</td>
</tr>
<tr>
<td>□ Not at all</td>
<td>□ I take just as much care as ever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things:</th>
<th>I feel restless as if I have to be on the move:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ As much as I always could</td>
<td>□ Very much indeed</td>
</tr>
<tr>
<td>□ Not quite so much now</td>
<td>□ Quite a lot</td>
</tr>
<tr>
<td>□ Definitely not so much now</td>
<td>□ Not very much</td>
</tr>
<tr>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind:</th>
<th>I look forward with enjoyment to things:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ A great deal of the time</td>
<td>□ As much as I ever did</td>
</tr>
<tr>
<td>□ A lot of the time</td>
<td>□ Rather less than I used to</td>
</tr>
<tr>
<td>□ From time to time but not too often</td>
<td>□ Definitely less than I used to</td>
</tr>
<tr>
<td>□ Only occasionally</td>
<td>□ Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful:</th>
<th>I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Not at all</td>
<td>□ Very often indeed</td>
</tr>
<tr>
<td>□ Not often</td>
<td>□ Quite often</td>
</tr>
<tr>
<td>□ Sometimes</td>
<td>□ Not very often</td>
</tr>
<tr>
<td>□ Most of the time</td>
<td>□ Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can sit at ease and feel relaxed:</th>
<th>I can enjoy a good book or radio or TV programme:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Definitely</td>
<td>□ Often</td>
</tr>
<tr>
<td>□ Usually</td>
<td>□ Sometimes</td>
</tr>
<tr>
<td>□ Not often</td>
<td>□ Not often</td>
</tr>
<tr>
<td>□ Not at all</td>
<td>□ Very seldom</td>
</tr>
</tbody>
</table>

Please check that you have answered ALL the questions

Thank you again very much for your help with this research
This form is for the partner of the patient

Research Questionnaire

The Evaluation of a Psychosocial Video

Thank you so much for agreeing to take part in this research. As a result of your help we hope that this research will lead to other people receiving better care in the future.

Please complete every item in this questionnaire. Read carefully the instructions for each section and, after you have finished, check that all questions have been answered.

Please find somewhere on your own to complete the questionnaire. As soon as you have finished, seal it in one of the envelopes provided and try to post it within 3 days of the day you received it.

**IMPORTANT**
For this research to be successful, it is extremely important that you complete all the questions on your own. In other words, without anyone helping you or influencing what you write.

Please do not help, or receive help from, your partner.

Remember: the term “your partner” in this questionnaire refers to the person you are married to, or living with.

Some of the questions may seem quite personal but please try to be as honest as you can possibly be. Remember that your answers will be kept entirely confidential and, as you can see, this form contains a code (i.e. not your name) which only the researcher understands.

Your details will not be revealed to anyone else.

Thank you again very much for helping with this research.
1. **Demographic questions** *(Please answer ALL the questions)*

1. Are you the patient ☐ or the partner of the patient ☐ *(tick one box)*

2. Are you Male ☐ or Female ☐ *(tick one box)*

3. Please state your age

4. If you have children, please state their sex and age
   *(for example: girl of 21, boy of 18, etc.)*

5. Please circle any children currently living with you at home

6. How many years have you been living with your partner? ☐ years

7. Are you married ☐ or “living together” ☐ *(tick one box)*

8. Have you been previously married *(or in an equivalent longterm relationship)*? YES ☐ NO ☐

9. Who is the major wage earner in your present relationship? Me ☐ My Partner ☐

10. What is the occupation of the major wage earner?

11. (a) Are you currently in work Full-time ☐ I don’t work ☐ *(tick one box)*
   (even if you have had to stop Part-time ☐ Unemployed ☐ *(tick one box)*
   recently due to the illness) Voluntary work ☐ Retired ☐

   (b) If you are in work, have you had to reduce the amount you work because of the illness? YES ☐ NO ☐

12. At what age did you leave full-time education?

13. At what point did your education finish? During:
   Secondary school ☐ *(tick one box)*
   College/technical college ☐
   University/Polytechnic ☐

14. Have you ever received any psychiatric or psychological treatment? YES ☐ NO ☐
   If so, please briefly state what the treatment was for:

15. Are you currently receiving any medication for
   anxiety ☐ none ☐ *(tick whichever boxes apply)*
   depression ☐
   other psychiatric condition ☐

16. Are you currently receiving any formal support *(e.g. counselling, therapist, self-help group)*? YES ☐ NO ☐
   If so, please specify
17. **Looking back on your life, have you had to cope with any of the following?**

(a) A brother, sister, parent or child of yours being diagnosed with cancer?  
   YES □ NO □  
   If yes, please specify, *with year & illness*  

(b) Receiving a diagnosis of cancer yourself?  
   YES □ NO □  
   If yes, please specify year & diagnosis  

(c) Receiving the diagnosis of a potentially life-threatening disease yourself?  
   YES □ NO □  
   If yes, please specify year & diagnosis  

(d) A period of more than one month when you have been seriously ill?  
   YES □ NO □  
   If yes, please specify year & diagnosis  

(e) A period of more than two weeks when you single-handedly had to look after someone else who was ill or very dependent?  
   YES □ NO □  
   If yes, *for how long*?  

(f) A period of more than two weeks when you were separated from both your parents before you were four years old?  
   YES □ NO □  

(g) A period of depression which interfered with your life (whether or not you were given treatment for it)  
   YES □ NO □  

(h) A period of stress or anxiety which interfered with your life (whether or not you were given treatment for it)  
   YES □ NO □  

18. Have you had any other major stresses to cope with over the past six months?  
   YES □ NO □  
   If yes, please specify  

   ..................................................................................................................  

19. When you are completely honest with yourself, who has been your most important* source of support since you learned of your partner's cancer?  

   My partner □  My daughter □  My sister □  
   My mother □  My son □  A male friend □  
   My father □  My brother □  A female friend □  

   * (Tick one box only)  

   Other (please specify relationship to you) □  
   Sex of this person:  

   ..............................................
20. How did your partner react to the news of the cancer?

How did you think the illness or treatment has affected him or her?

21. How stressful do you think it has been for your partner to find out about the cancer?

0 Not at all stressful
1 Slightly stressful
2 Moderately stressful
3 Very stressful
4 Extremely stressful

(Tick one box only)

22. Since the illness, has your relationship with your partner changed at all? Overall, would you say it has got better, worse, or hasn’t changed?

1 A lot worse
2 A bit worse
3 Hasn’t changed
4 A bit better
5 A lot better

(Tick one box only)

In what way?

23. How supportive do you feel your partner has been to you since the illness was diagnosed?

0 Not at all
1 Slightly supportive
2 Moderately supportive
3 Very supportive
4 Extremely supportive

(Tick one box only)
24. How critical towards you has your partner been since the illness?

0  Not at all  
1  Slightly critical  
2  Moderately critical  (Tick one box only)  
3  Very critical  
4  Extremely critical  

25. How withdrawn from you has your partner been since the illness?

0  Not at all  
1  Slightly withdrawn  
2  Moderately withdrawn  (Tick one box only)  
3  Very withdrawn  
4  Extremely withdrawn  

26. The dots on the following line represent different degrees of happiness in your relationship with your partner. The middle point, “happy”, represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

Extremely Fairly A little Happy Very Extremely Perfect
Unhappy Unhappy Unhappy Happy Happy

27. Please write the appropriate number beside each question below according to this scale:

a. How often do you and your partner quarrel?
b. How often do you and your partner “get on each other’s nerves”?
c. How often do you discuss or have you considered divorce, separation, or terminating your relationship?
d. Do you ever regret that you married/lived together/had a relationship?
e. In general, how often do you think that things between you and your partner are going well?

Please complete every question
### 3. PROBLEMS AND COMPLAINTS

Below is a list of problems and complaints that people sometimes have. For each item, select one of the numbers that best describes HOW MUCH DISCOMFORT THAT PROBLEM CAUSED YOU DURING THE PAST MONTH. Write one number in the space to the right of each problem.

The numbers refer to these phrases:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>A little bit</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Quite a bit</td>
</tr>
<tr>
<td>4</td>
<td>Extremely</td>
</tr>
</tbody>
</table>

### HOW MUCH WERE YOU DISTRESSED BY:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nervousness or shakiness inside</td>
<td>16. Feeling fearful</td>
</tr>
<tr>
<td>2</td>
<td>Loss of sexual interest or pleasure</td>
<td>17. Heart pounding or racing</td>
</tr>
<tr>
<td>3</td>
<td>Feeling easily annoyed or irritated</td>
<td>18. Feeling hopeless about the future</td>
</tr>
<tr>
<td>4</td>
<td>Feeling low in energy or slowed down</td>
<td>19. Feeling tense or keyed up</td>
</tr>
<tr>
<td>5</td>
<td>Thoughts of ending your life</td>
<td>20. Having urges to beat, injure or harm someone</td>
</tr>
<tr>
<td>6</td>
<td>Trembling</td>
<td>21. Having urges to break or smash things</td>
</tr>
<tr>
<td>7</td>
<td>Crying easily</td>
<td>22. Feeling everything is an effort</td>
</tr>
<tr>
<td>8</td>
<td>Feelings of being trapped or caught</td>
<td>23. Spells of terror or panic</td>
</tr>
<tr>
<td>9</td>
<td>Suddenly scared for no reason</td>
<td>24. Getting into frequent arguments</td>
</tr>
<tr>
<td>10</td>
<td>Temper outbursts that you could not control</td>
<td>25. Feeling so restless you couldn't sit still</td>
</tr>
<tr>
<td>11</td>
<td>Blaming yourself for things</td>
<td>26. Feelings of worthlessness</td>
</tr>
<tr>
<td>12</td>
<td>Feeling lonely</td>
<td>27. The feeling that something bad is going to happen to you.</td>
</tr>
<tr>
<td>13</td>
<td>Feeling down</td>
<td>28. Shouting or throwing things</td>
</tr>
<tr>
<td>14</td>
<td>Worrying too much about things</td>
<td>29. Thoughts and images of a frightening nature</td>
</tr>
<tr>
<td>15</td>
<td>Feeling no interest in things</td>
<td></td>
</tr>
</tbody>
</table>
4. YOUR RELATIONSHIP

Please answer each question below by circling the number which best represents your feelings about your partner. The second part of each question asks you to rate how you would like things to be if they were exactly what you hoped for (your ideal). As before, put a circle around the one number which shows what you feel.

1a) Can you trust, talk to frankly, and share your feelings with your partner? Never Sometimes Always

1 2 3 4 5 6 7

b) What rating would your ideal be?

2a) Can you lean on and turn to your partner in times of difficulty? Never Sometimes Always

1 2 3 4 5 6 7

b) What rating would your ideal be?

3a) Does he/she give you practical help? Never Sometimes Always

1 2 3 4 5 6 7

b) What rating would your ideal be?

4a) Can you spend time with him/her socially? Never Sometimes Always

1 2 3 4 5 6 7

b) What rating would your ideal be?

5. VIEWS ABOUT YOURSELF

Please enter the number of the response that is closest to how you currently feel about yourself regarding each of the following statements.

1  I feel that I am a person of worth, at least on an equal plane with others

2  I feel that I have a number of good qualities

3  All in all, I am inclined to feel that I am a failure

4  I am able to do things as well as most other people

5  I feel I do not have much to be proud of

6  I take a positive attitude towards myself

7  On the whole, I am satisfied with myself

8  I wish I could have more respect for myself

9  I certainly feel useless at times

10  At times I think I am no good at all
Please read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling IN THE PAST WEEK. 
Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.
TICK ONLY ONE BOX IN EACH SECTION

I feel tense or wound up:
- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:
- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

I get a sort of frightened feeling, as if something awful is about to happen:
- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I can laugh and see the funny side of things:
- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:
- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful:
- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:
- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down:
- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all
- Occasionally
- Quite often
- Very often

I have lost interest in my appearance:
- Definitely
- I don't care so much as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move:
- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things:
- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic:
- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme:
- Often
- Sometimes
- Not often
- Very seldom

Please check that you have answered all the questions

Thank you again very much for your help with this research
Please complete this entirely on your own

Facing it Together

This video is concerned with the problems of giving support within a relationship when one partner has cancer.

(For each question below, look at both extremes and mark the line with an X at the point which best reflects what you feel)

1. How important do you feel this theme is in general?
   Not at all _______________________________________________ Extremely important

2. How relevant do you feel this theme is to your relationship with your partner?
   Not at all _______________________________________________ Extremely relevant

3. How relevant to your relationship do you imagine your partner found the video?
   Not at all _______________________________________________ Extremely relevant

4. How helpful to you would it be if both you and your partner could follow the advice in this video completely?
   Not at all ___________________________________________________ Extremely helpful

5. How supportive towards your partner do you feel you have been since the diagnosis?
   Not at all _______________________________________________ Extremely supportive

6. What barriers or obstacles, if any, do you see preventing you and your partner following the advice in this video?


8. Are there any other comments you would like to make about this video?


Thank you again for your kind help with this research
Note: This questionnaire should be completed last

### THE VIDEO

1. How many times did you watch the video? □

2. Of these times, how many times did you watch the video with your partner? □

3. Do you believe that the video caused you both to talk together more? YES □ NO □
   
   **Comments:**

4. Do you believe that watching the video led you to support your partner more? YES □ NO □

5. Do you believe that watching the video led your partner to support you more? YES □ NO □

6. Looking back, do you feel that the video was helpful to your relationship? YES □ NO □

*In the following questions, look at both extremes and mark anywhere along the line with an X, but at the point which best reflects what you feel*

7. How helpful did you find the advice in the video? Not at all helpful ________________________ Extremely helpful

8. How helpful was it hearing the experiences of the patients on the video? Not at all helpful ________________________ Extremely helpful

9. How helpful was it hearing the advice of the "professional expert"? Not at all helpful ________________________ Extremely helpful

10. How helpful was the leaflet that accompanied the video? Not at all helpful ________________________ Extremely helpful

11. Can you suggest anything that might improve the video?

12. Do you believe that a video like this should be given to other couples when one of them has cancer?

13. Are there any other comments you wish to make? *(please continue on reverse if necessary)*
Appendix E: Leaflet — "Facing it together"
• Try to **listen more than to talk**
Try to understand what your partner is feeling and saying and, when it's your turn to speak, begin by showing them that you've heard what they have said, perhaps by repeating some of it back to them. Some people have great difficulty being quiet and listening to the real concerns of their partner, yet this simple act is extremely powerful and important.

• **People are not always what they seem!**
Sometimes people's feelings are not clear from the way they are behaving. For example, someone who seems angry and short-tempered may, in fact, be feeling worried or stressed.

• **Try not to be critical**
What other people feel is neither right nor wrong. It may not be what you would feel in the same situation but what is important is that your partner knows you are trying to understand their experience.

• **Try to show your partner how much they mean to you**
Most couples, after being together for a few years, forget to show their appreciation of one another. We tend to take each other for granted and forget to make each other feel special (remember how good you and your partner made each other feel when you first met). Try to let your partner know how important they are to you and how much you care about them.

---

**If you are 'the patient'...**

• **Talk to your partner and other people on a regular basis about what you feel and think**
Simply talking to someone about your feelings is not being a 'burden' on them; would you feel they were being a burden on you if they were a patient and came to talk to you? Get support from anyone you feel comfortable with. We are not encouraging you to get all your support from your partner.

• **Let your partner know when it's important to you**
Don't simply assume your partner understands what you are feeling. Let your partner know that what you want to talk about is important to you.

**If you are 'the partner'...**

• **Don't withdraw**
This is the time when your partner (the patient) may need you most so don't make yourself scarce. Listening can be tiring but it can make an enormous difference to someone dealing with a lot of stress. Don't worry about saying the wrong thing – the most important thing is to stay involved.

• **Find someone else you can talk to as well**
Find someone else to talk to about how things have changed for you recently, and make this support a regular part of your life over the next few months. You may be feeling hurt that your partner seems to be caring about you less at the moment but this may be because of the stress they are under. You may find it easier to support them if you have someone else to listen to you as well.

---

This leaflet is part of the research project: An Evaluation of Two Preventive Psychosocial Videos, conducted by [researchers] at the Bristol Oncology Centre.
Please do not copy or reproduce this leaflet in any way.

---

**Facing it together**

Please read this leaflet after watching the video, and filling out the short questionnaire, that accompany it, and then discuss its contents with your partner.

Try to follow the advice in this leaflet as well as you can, but always follow your feelings about what is right for you.

Try to keep this leaflet safe over the next few months and refer to it from time to time.

Your help with this research is very much appreciated.
not simply the patient...

The following advice applies to both of you:

- Both of you cope better and face different things together.
- The more you are both feeling and thinking about what you are doing and how you are feeling and thinking, the better your relationship is being repaired.
- The more you are doing together, the better you are doing together. But if you are not doing together, you may not be doing as well as you could be.
- The more you are doing together, the better you are doing together. But if you are not doing together, you may not be doing as well as you could be.
- The more you are doing together, the better you are doing together. But if you are not doing together, you may not be doing as well as you could be.
- The more you are doing together, the better you are doing together. But if you are not doing together, you may not be doing as well as you could be.
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- The more you are doing together, the better you are doing together. But if you are not doing together, you may not be doing as well as you could be.
Title: Illusory Correlations in Paranoid and Nonparanoid Schizophrenia

Supervisor: Dr D.R. Hemsley, Institute of Psychiatry, University of London

Degree awarded: November 1981
UNIVERSITY OF LONDON

JAMES HUGH BRENNAN

of

INSTITUTE OF PSYCHIATRY

having completed the course of study approved by the University and

passed the prescribed examinations as an Internal Student has

this day been admitted by the Senate to the degree of

MASTER OF PHILOSOPHY

18 NOVEMBER 1981

Vice-Chancellor
ILLUSORY CORRELATIONS IN PARANOID AND NONPARANOID SCHIZOPHRENIA

James Hugh Brennan

Institute of Psychiatry

Dissertation submitted in part fulfilment of the requirements of the Master of Philosophy Degree in Clinical Psychology, University of London.

August 1981.
Abstract.

Nineteen hospitalized schizophrenics were divided into paranoid and nonparanoid groups on the basis of their scores on two instruments designed to measure this distinction. These patients were compared with a group of ten normals as to their tendency to make illusory correlations, a phenomenon in which subjects perceive a degree of order in an ambiguous sequence of data. It was hypothesized that paranoid schizophrenics would make stronger illusory correlations than normals because of the predominance of their schemata when processing information. It was further hypothesized that nonparanoids would make weaker correlations than normals because of their impaired ability to establish conceptual categories with which to organize incoming information.

Of the three methods of allocation used to divide patients into paranoid and nonparanoid groups on the basis of their paranoid-nonparanoid scores, only one produced any notable differences between groups. These differences, while failing to attain statistical significance, were in accordance with the hypotheses. Of the four tasks administered, the paranoid group made particularly strong illusory correlations on the one which included stimuli of relevance to individuals with paranoid delusions. The results were discussed with reference to the problems of assessing the paranoid-nonparanoid distinction, the study's methodological shortcomings, and the clinical relevance of the findings.
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I would like to thank Dr David Hemsley for his excellent supervision, and for maintaining a calm perspective which I sometimes lacked.

Thanks also must go to Dr Brian Everitt for his statistical help and advice.

Finally, many thanks to Ms Jeni Trigona for spending so much time and cheerful diligence typing this dissertation.
A. 1. INTRODUCTION

While thought disorder has long been regarded as a primary feature of schizophrenia, it is nonetheless worthwhile asking what relevance the study of cognitive impairment has for a better understanding of schizophrenia (c.f. Cromwell, 1978). The clinical symptoms of schizophrenia have been elusive and fluctuating, and their prognostic significance disappointing. One may well question whether the concepts of attention and information processing offer a more promising approach. Some, at least, believe that "to explain schizophrenia, perhaps these more subtle, more tolerable but probably more stable, manifestations are more important than the variably expressed incursive symptoms that jar the tolerance of most people on earth" (Cromwell, 1978, p.220).

Cromwell (1978) identifies five distinct aims of cognitive research into schizophrenia. Firstly, there is the attempt to specify a single or pattern of cognitive dysfunction from which the various symptoms resulting in a diagnosis of schizophrenia might be derived. Secondly there is the attempt to find different cognitive abnormalities among different subgroups of schizophrenic patients. Thirdly, cognitive measures have been widely used in longitudinal studies of high-risk children in an attempt to identify factors which might predict later psychiatric breakdown. Fourthly there has been the study of vulnerability factors across the lifespan of the single individual rather than across the disturbed individual and his relatives. These indices would occur prior to, during and after becoming schizophrenic. Finally, cognitive variables have been used to track the course of change in response to treatment.

We shall be examining some of the research described under the first two of these aims and begin by a short and selective historical review of the cognitive approach to schizophrenia.
2. COGNITIVE ABNORMALITY IN SCHIZOPHRENIA

(a) Early Work

It was not until Emil Kraepelin’s famous textbook *Psychiatrie, Ein Lehrbuch fur studirende und arzte*, published in six editions between 1883 and 1927, that an internationally accepted nosology of psychiatry emerged. In it Kraepelin elevated the purely descriptive term "dementia praecox" to the status of a mental disease, of unknown origin but with specific symptoms and a predictable course. Kraepelin’s description of the early symptoms of dementia praecox emphasized a particular pattern of psychological deficits (Crider, 1979). Patients showed poor ability to focus attention and were often distracted by momentary or accidental stimuli. Thought processes showed incoherence and looseness; in mild cases this appeared as rapid transitions from one thought to another without any logical bridge while in more severe cases it appeared as almost total incoherence of speech. In addition, patients tended to show poor judgement, delusional beliefs, blunting of affect and a deterioration in self-care.

Kraepelin’s view of dementia praecox as an apparent dementia occurring before old age and with no associated brain impairment was soon overshadowed by Bleuler’s 1911 concept of schizophrenia. While Kraepelin attempted to isolate various forms of the disorder on the basis of symptom clusters, or syndromes, Bleuler was the first to attempt to specify a single underlying defect which could account for all symptoms of the disorder: "The disease is characterized by a specific type of alteration of thinking, feeling and relation to the external world which appears nowhere else in this particular fashion". (Bleuler 1950, p.9).

In coining the term schizophrenia (split-mind) Bleuler was suggesting therefore that the disconnectedness or fragmentation of thought, feeling and interpersonal interaction is the essence of the disorder. Thus, one of the fundamental symptoms of schizophrenia described by Bleuler, which have come to be known as his "four A's", is the disruption of the associative processes whereby the connections between ideas enable normals to organize and interrelate many single thoughts and exclude irrelevant thoughts (Hemsley, Note 1).
Bleuler also made the important distinction between primary and secondary schizophrenic symptoms. He defined primary symptoms as direct manifestations of the underlying organic disease, such as the disturbance of association, whereas secondary symptoms represented adjustments or attempts at adaptation to the primary disturbance. This view of symptoms as adjustment responses to the primary cognitive impairment can be seen in the work of more recent investigators (e.g., Hemsley, 1977) and will be considered below.

Since Bleuler, other clinicians have suggested alternative concepts as constituting the primary cognitive disturbance in schizophrenia. Perhaps most notable among these was the term "overinclusion" which Cameron (1939) used to describe schizophrenic patients' frequent inability to limit their attention to the relevant stimuli of a task, and their tendency to "overinclude" irrelevant stimuli in, for example, object sorting tasks.

Such formulations led to attempts to isolate specific performance deficits peculiar to schizophrenia, a psychological deficit being defined by Hunt and Cofer (1944) as the decrement in performance or the loss of efficiency shown by psychiatric patients relative to normals on intellectual and laboratory tasks. However the early research on cognitive deficits lacked an adequate model of normal cognitive functioning and the tasks used tended to be ambiguous in terms of the particular cognitive functions being tapped.

(b) The Information Processing Approach.

In the last few years information processing theory has become the dominant research paradigm for studying adult cognitive processes. Having its origins in normal psychology, the information processing model offers a more explicit relationship between task performance and inferred cognitive function. The major assumption of this approach is that perceptual and cognitive activities can be represented as a series of transformations of information, and thus the aim of this approach is to clarify the specific operations that occur between stimulus and response, and to describe the nature and limits of these processes (Hemsley, Note 1).
Since these stages of processing are not directly observable their existence must be inferred from performance on a number of tasks and by using a procedure of converging operations. More recent studies of schizophrenics' cognitive impairment are thus tending to employ the design of manipulating a single variable with the object of increasing the load on a particular stage of processing. If no differential effect on reaction time is found between a schizophrenic and a control group it is argued that the particular stage is not implicated in schizophrenic cognitive impairment.

In 1958 Broadbent proposed a model of information processing whereby a hypothetical filter mechanism was presumed to screen irrelevant stimuli from a limited capacity decision channel. The filter was seen to act in an all or none fashion on the basis of the physical attributes of classes of stimuli. This model resulted in two views as to the nature of cognitive disturbance in schizophrenia. The first proposed that schizophrenics possess a defective filter mechanism (McGhie and Chapman, 1961; Neale and Cromwell, 1970) while the second maintained that schizophrenics are slow in processing information (Yates, 1966).

While these two approaches to schizophrenic cognitive impairment generated much research it soon became apparent that Broadbent's (1958) model required modification. His more recent model (Broadbent, 1971, 1977), building upon Treisman's (1960) earlier theory, emphasizes the probabilistic aspects of information processing. The limited capacity decision channel is seen to receive "evidence", not determinate information. The stimulus is the first of three variable states which occur at points along the information processing continuum. This simply refers to the state of the environment which actually occurs on a given occasion. The evidence, the second variable state, is what actually results from the stimulus and is defined as the particular input to the limited capacity channel. "Filtering" is seen as the process which determines the nature of the evidence resulting from a stimulus, and, like Treisman's concept of attenuation, is not an all-or-none activity; evidence from other sources only receives less
weight. Filtering causes the evidence to depend to an increased extent on those stimulus events which have some physical feature in common.

The third variable in Broadbent's 1971 model is described as "category state". Category states are the channel outputs which result from the input of particular pieces of information. "Pigeon-holing is the term coined by Broadbent to refer to the process whereby category states result from evidence. This corresponds to a change in response bias or the operation of a response set. Thus pigeon-holing increases the chances of one category state occurring rather than another when it is preceded by a larger class of evidence. Thus, listening for particular words, regardless of their source would involve the process of pigeon-holing.

This concept of pigeon-holing represented an important shift in the meaning or location of the mechanism of attention moving it further into the conceptual processes (Magaro, 1980). More recent theories, to be discussed below take this shift even further and consider attention to be a circular flow between percept and concept. "Categorizing" is the process by which the nervous system adjusts so as to allocate certain category states to certain stimulus events. "Typically any of several different stimulus events will elicit any one category state. This may happen because some stimulus features will be treated as irrelevant, both red and green squares eliciting the response "square". It may also happen because two or more different combinations of features are allocated to the same category; as when tall broad men and short slender ones may both qualify as "well proportioned" although the other combinations would not. Thus categorizing involves both input and output selection" (Broadbent, 1971 p.xi).

In a review of schizophrenics' disturbances of selective attention within Broadbent's 1971 model, Hemsley (1975) suggested that defective filtering should act to reduce the discrepancy of performance on a short term memory task between the condition of pre-instruction as to the relevant material and that of post-instruction, provided that a clear physical cue separates the relevant and irrelevant items. Normal subjects show a clear advantage
of pre-instruction (stimulus set) on such tasks (Broadbent, 1970). Hemsley and Zawada (1976) however showed that while normals showed a significantly greater improvement with pre-instruction than the schizophrenic or depressed groups, the psychotic groups did not differ. The authors suggested that the filter defect may not be specific to schizophrenia but may be more closely related to a severity of illness dimension "not important causally in many of the behavioural abnormalities seen in schizophrenia" (Hemsley and Zawada, 1976, p.460).

While there is little evidence of a disturbance of pigeon-holing in schizophrenia in the literature, Hemsley and Richardson (1980) devised a study which required subjects to shadow one of two simultaneously presented prose passages. The messages were indistinguishable on the basis of physical cues and therefore allowed no possibility for the operation of the filter mechanism. Since successful performance required subjects to use contextual variables in determining selection of the appropriate response, it thus depended upon the pigeon-holing mechanism whereby category state thresholds may be raised or lowered according to the nature of the evidence derived from the preceding context. Schizophrenics, depressives and normals, matched for verbal Intelligence Quotient and shadowing ability without distraction, were tested using two rates of presentation (60 w.p.m. and 100 w.p.m.). Results showed that schizophrenics performed significantly worse than both other groups, a finding consistent with a defect at the pigeon-holing stage.

The pigeon-holing mechanism is considered to operate not solely within laboratory tasks aimed at assessing selectivity but across all areas of cognitive functioning. "In its role as a bias towards certain categories of responses in real life situations, rather than those biases imposed by task instructions, it may be viewed as a way of making use of the redundancy and patterning in environmental input to reduce information processing demands" (Hemsley, Note 1). As Broadbent (1977) observed, this kind of attention "selects some of the possible interpretations that a man may hold about the world and eliminates
others as candidates for use in the particular situation" (p.110). Thus when a stimulus is expected the attentional biases will act to improve performance though when the stimulus is unexpected the normal biases may serve to impair performance.

While Broadbent's (1971) model has generated research aimed at locating the source of cognitive abnormalities in schizophrenia (i.e. a defect at the filtering or pigeon-holing stages), other work has looked at the strategies of adaptation that the schizophrenic may employ to cope with these abnormalities. For example, Hemsley (1977) has suggested several methods of adjustment that the schizophrenic may make to a state of "information overload" caused by a defective filter mechanism and/or slowness in response selection. One such method is that of "omissions" whereby category state thresholds are raised generally and indiscriminately, seen clinically as underresponsiveness. Another strategy of adaptation proposed by Hemsley (1977) is "approximation" in which a number of stimuli receive the same response rather than each receiving a differential response.

According to the Broadbent model there are two ways in which such a reduction in the number of response alternatives may occur. In the first the learned use of simplified categories may result in the application of a simple global category to different stimulus events. For example, a square, rectangle and trapezium all may be categorized more simply as four-sided shapes. This would therefore constitute a problem at the categorizing stage. Alternatively however the problem may be occurring in the more rapid process of pigeon-holing. In this case the individual raises the category state thresholds to certain stimuli to such an extent that the individual fails to respond to them altogether. As yet it is not clear which or whether both of these processes may be operative in approximation.

According to Hemsley (1977), the approximation mechanism of adaptation may be useful to our understanding of delusional systems. One example of schizophrenics approximation or simplified categorizing can be seen
in an experiment by Koh and Shears (1970) in which schizophrenics and normal subjects were compared on their preferences for musical excerpts, using both category ratings and magnitude estimations. Schizophrenics showed less consistent music preferences, but more interestingly they also reduced the number of response alternatives employed. The patients tended to be constricted or stereotyped in their preferences indicating that the patients used wider categories, employing fewer of them but using them more frequently than did normal subjects. Such a finding is not inconsistent with the views of Magaro (1980) whose approach will be discussed in a subsequent section.

Returning to Cromwell's (1978) views on the aims of studying cognitive abnormalities in schizophrenia, we are reminded of the long-held observation that undifferentiated schizophrenic groups have high inter-subject, as well as intrasubject variability on most measures. However, by identifying discrete subgroups within schizophrenia the variability would be less within subgroups. In addition should a subgroup be found which differs significantly in one direction while another subgroup differs significantly in the opposite direction from a normal control group this would represent a theoretically provocative finding. One would then be left to determine whether the index for grouping is identifying different disorders or different cognitive styles which may be manifest in a single pathological state.
3. THE PARANOID - NONPARANOID DISTINCTION IN PSYCHIATRY.

Kraepelin (1919) was explicit about distinguishing the paranoid from other forms of dementia praecox. He noted that paranoia was a primary disease of the intellect which had the secondary phenomena of delusions. The main characteristic of the paranoid was "the insidious development of a permanent and unshakable delusional system resulting from internal causes accompanied by a perfect presentation of clear thinking, willing and acting" (Kraepelin, 1976, p. 212 - 213). However while Kraepelin, and later Bleuler, accepted the possibility of a separate condition called paranoia, neither considered it a separate category from the nonparanoid types. The World Health Organization's International Classification of Diseases manual (1978), however distinguishes between schizophrenia of the paranoid type, simple paranoid state and paranoia:

295.3 Schizophrenia, Paranoid type.
The form of schizophrenia in which relatively stable delusions, which may be accompanied by hallucinations, dominate the clinical picture. The delusions are frequently of persecution but may take other forms, (for example of jealousy, exalted birth, Messianic mission, or bodily change). Hallucinations and erratic behaviour may occur; in some cases conduct is seriously disturbed from the outset, thought disorder may be gross, and affective flattening with fragmentary delusions and hallucinations may develop.

297.0 Paranoid state, simple.
A psychosis, acute or chronic, not classifiable as schizophrenia or affective psychosis, in which delusions, especially of being influenced, persecuted or treated in some special way, are the main symptoms. The delusions are of a fairly fixed, elaborate and systematized kind.

297.1 Paranoia.
A rare chronic psychosis in which logically constructed systematized delusions have developed gradually without concomitant hallucinations or the schizophrenic type of disordered thinking. The delusions are mostly of grandeur (the paranoiac prophet or inventor), persecution or somatic abnormality.
Prior to 1950 researchers typically reported results for schizophrenia as a whole. More recently the paranoid – nonparanoid distinction has been increasingly employed as the need for more homogenous groups of schizophrenics has emerged. A subtle change is the use of schizophrenic and paranoid diagnostic labels is also evident in hospital diagnoses, probably occurring without awareness of the empirical results supporting the distinction (Magaro, 1980). American hospital diagnoses of schizophrenia presently tend to include labels of paranoid or undifferentiated rather than the previous labels of catatonic, hebephrenic or simple. Hence both in clinical research and practice there has been a gradual movement towards the dichotomy of paranoid and nonparanoid within the general label schizophrenia.

Venables and O'Connor (1959) attempted to define these categories empirically and on the basis of studying one hundred male chronic schizophrenics they produced a scale of four items designed to identify patients exhibiting paranoid symptoms. These are:

(1). Does he tend to suspect or to believe on slight evidence or without good reason that people and external forces are trying to or now do influence his behaviour and control his thinking?

(2). Does he tend to suspect or to believe on slight evidence or without good reason that some people talk about, refer to or watch him?

(3). Does he tend to suspect or to believe on slight evidence or without good reason that some people are against him (persecuting, conspiring, cheating, depriving, punishing) in various ways?

(4). Does he have an exaggeratedly high opinion of himself or an unjustified belief or conviction of having unusual ability, knowledge, power, wealth or status?

(from Venables and O'Connor, 1959, p. 817-819)

As Berkowitz (1981) points out, however, in the past twenty years this scale has rarely been used.

Zigler, Levine and Zigler (1976) observe that
"within the clinical folklore that has accompanied this
descriptive tradition, there has been the view that the
paranoid schizophrenic is a less disorganized and patho-
logical form than are the other types of schizophrenia"
p.109. Goldberg, Schooler and Matteson (1968) suggest
that paranoid symptoms are also more amenable to
treatment. Strauss (1974) found that paranoid schizo-
phrenics had shorter and fewer hospital admissions than
nonparanoid patients. Evans, Goldstein and Rodnick (1973)
however found that paranoid patients returned to hospital
significantly more often than nonparanoids in the six
months after discharge though the relationship was not
observed during the second six months.

The literature on the premorbid personality criterion
for distinguishing between paranoid and nonparanoid
patients has been reviewed by Cromwell (1975) and Houlihan
(1975). Although there has been no consistent association
between premorbid personality and paranoid and nonparanoid
groups (Berkowitz, 1981), Goldstein, Held and Cromwell
(1968) found that while good premorbs could be either
paranoid or nonparanoid, poor premorbs were always
nonparanoid. Furthermore, Houlihan (1975) maintains that
in general the results suggest that paranoid schizophrenic
patients are less impaired than nonparanoid. Tsuang,
Fowler, Cadoret and Monelly (1974) found that, compared to
paranoids, nonparanoid schizophrenics had an earlier age
of onset, spent longer in hospital, and showed more thought
disorder and catatonic traits.

In addition to the premorbid personality criterion,
attention must be paid to the level of pathology as
represented by the process-reactive dimension in any
examination of the paranoid - nonparanoid distinction. A
study by Heilbrun and Heilbrun (1977) shows how differences
in the paranoid condition coincides with levels of pathology.
Using a content analysis of delusions they compared reactive
and process paranoid schizophrenics and found that the
delusions of the reactives were more integrated, varied
in content, actively orientated towards the environment
and less autistic. In other words the reactive paranoid
showed better organization and greater articulation but the greater the pathology the more the paranoid resembled the disorganized thought process of the nonparanoid schizophrenic. Thus, "not controlling for the level of pathology in selecting a sample of paranoids and (non-paranoid) schizophrenics may tend to produce samples of integrated and nonintegrated patients which would obscure the differences between the two subgroups" (Magaro, 1980, p.135).

Berkowitz (1981) points to some problems which she claims strike at the validity of the paranoid - nonparanoid distinction. Firstly she points out that there has been little consistency in the criteria used for placing patients in one or other category. Much of the research to date has used diagnoses based upon clinical judgement, thus making cross-study comparisons problematic. Secondly, there has been a "ragbag" approach to defining the nonparanoid group. Some studies have used nonparanoid patients and some hebephrenics though it is far from clear that one may justifiably generalize from hebephrenics to all nonparanoids. Berkowitz's final criticism is that the clinical status of patients does not appear to be stable, that schizophrenic patients change from a paranoid to a nonparanoid diagnosis. Depue and Woodburn (1975) found that in chronic cases paranoid symptoms tend to disappear so that the diagnosis of the original sample of paranoid schizophrenia is changed to nonparanoid by the time of the second hospital admission, about six years later.

With reference to this last criticism, Berkowitz is correct in suggesting that if clinical status does change, characteristics such as premorbid personality and outcome cannot be sensibly examined. However, in as far as changes in schizophrenic symptoms reflect changes in methods of adaptation to prolonged high levels of information overload (Hemsley, 1977), the distinction may still be usefully related to cognitive abnormalities.

With reference to Berkowitz's earlier points concerning the literature's lack of a consistent method of categorizing schizophrenic patients into paranoid and nonparanoid groups, it must be pointed out that reliable
and valid measures do exist. For example, the Maine Paranoid-Schizophrenic Rating Scale, initially developed by Vojtisek (1976), is an adaptation of the Venables and O'Connor (1959) scale (see above) and Overall and Gorham's (1962) brief psychiatric rating scale. It consists of a five-item scale for paranoia and another five-item scale for (nonparanoid) schizophrenia. Each item requires rating a single symptom on a five-point labelled scale. The ratings are summed for each scale to yield a score for paranoia and a score for schizophrenia. The Maine Scale was examined in three separate studies using hospitalized psychiatric patients in which adequate test-retest (paranoid: \( r = 0.89 \); nonparanoid: \( r = 0.73 \); over four days, \( N = 26 \)) and independent inter-rater reliability (agreement rate = 85 percent) was obtained (Magaro, Abrams and Cantrell, 1981).

In an examination (Magaro et al., 1981) of construct validity, high scores on the nonparanoid subscale were associated with external locus of control, poor performance on the Stanford-Binet Vocabulary, Expanded Similarities, Embedded Figures Test, conceptual overinclusion, slow reaction time, deviant word associations, and poor recall of word associations. Scores on the paranoid scale did not correlate with any of these performance measures. These same authors studied the concurrent validity of the Maine Scale and found the paranoid and nonparanoid subscales correlated significantly with the corresponding scales of the Symptom Rating Scale and the Symptom-Sign Inventory and other instruments, but was found to be better able to discriminate between paranoid and nonparanoid schizophrenics than any of these scales.

Another potentially useful instrument for assessing the paranoid - nonparanoid dimension is the Delusion Symptom-State Inventory (DSSI) developed by Foulds and Bedford (Bedford and Foulds, 1977). The DSSI is a self-report version of the Symptom-Sign Inventory (SSI) (Foulds and Hope, 1968) consisting of eighty four items using a true-false format. True statements are further subdivided into three categories describing the degree of
distress (e.g. a bit, a lot, unbearably) that the reported item causes the patient. The eighty-four items constitute four classes containing all twelve sets or clusters of symptoms, each set being composed of seven items. Within class 3, integrated psychosis, are three sets of items describing delusions of persecution (dP), delusions of grandeur (dG) and delusions of contrition (dC). These in turn refer to the putative clinical syndromes of paranoid disorder, mania and psychotic depression. Class 4, non-integrated psychosis, contains only one set, delusions of disintegration (dD) and refers to schizophrenia.

Foulds' theory of psychiatric illness, upon which the DSSI is based, posits that the four classes of personal illness, are of a hierarchical nature, ranging from dysthymic states through neurotic symptoms, integrated delusions to the most severe, delusions of disintegration. The relationship between the classes is such that when a patient's membership of a class is established he will necessarily be a member of all classes lower in the hierarchy. This model is therefore quite different from that employed in the Maine Scale since any patient with a score of four or more on the delusions of disintegration set is not only classified under the non-integrated psychosis class (schizophrenia) but, according to the model, also should have scored above the cut-off to be classified under the integrated psychosis class. Membership in the schizophrenic group therefore should not preclude membership in the paranoid group. The other, more obvious difference between the scales is that the Maine Scale is completed by a psychiatrist on the basis of interview and case-notes while the DSSI is completed by the patient on the basis of his phenomenological experience. Despite these differences, the Maine Scale has been cross-validated with the corresponding scales of the SSI to yield significant correlations (Paranoid scales: $r = .69$, $p < .001$; Nonparanoid scales: $r = .43$, $p < .01$; $N = 47$) (Magaro, Abrams and Cantrell, 1981), thus suggesting that the two scales may be reflecting similar aspects of the dimension in question.
Validation studies of the DSSI have included an investigation (Bedford and Foulds, 1977) to ascertain what percentage of the allocation of 16 senior psychiatrists and 9 experienced psychologists would agree with the a priori allocation of items to the clinical syndromes. It was found that for six (including dP and dD) of the twelve sets all seven items were allocated by a majority of judges to the expected syndrome. In another study (Bedford and Foulds, 1978), raters, ranging from trainee psychiatrists to consultants rated 96 inpatients on a four-point scale from 0 (absent) to 3 (outstanding) for each particular syndrome. Results showed that a majority of judges allocated 82 out of the 84 items to the same sets as the authors had done. Moreover there was a significant relationship between ratings and DSSI scores on the delusions of persecution (p < .01) and delusions of disintegration sets (p < .01). Presumably because of its unusual theoretical basis, the DSSI has not been cross-validated with other psychometric instruments and there are no data available on its test-retest reliability. Being of unknown reliability its use as a measure of the paranoid - nonparanoid dimension is therefore limited for the present, though as a phenomenological counterpart it may be fruitfully employed in conjunction with the Maine Scale.
4. COGNITIVE ASPECTS OF THE PARANOID - NONPARANOID DIMENSION.

"In general, the essence of the cognitive aberration seems to be disorganization in the nonparanoid and hyperorganization in the paranoid". (Magaro, 1980, p.142)

"The paranoid pattern of response may represent an over-reactive protection against the underlying pressure towards disorganization which characterizes the psychosis. The hebephrenic (nonparanoid) apparently gives way to these forces whereas the paranoid attempts to organize his resources to fight these disruptive trends". (Shakow, 1971, p.309)

Summarizing psychodiagnostic research on conceptual performance, Lothrop (1961) noted that paranoid schizophrenics consistently have been found to display less conceptual impairment than nonparanoid schizophrenics. On the whole the paranoid's conceptual capacity remains relatively intact.

Payne, Caird and Laverty (1964) found that paranoids tend to overinclude in their conceptualizations while others (Abrams, Tainter and Lhamon, 1966) have noted that they tend to reach erroneous conclusions quickly rather than waiting for more information. More recent research also lends weight to the notion that the paranoid differs from the nonparanoid by attributing meaning according to rigid conceptual expectations. For example, Forgus and De Wolfe (1974) found that paranoids, but not nonparanoids, tended to respond to the Logical Consequences Test with dominant concepts predicted from their delusions.

Basing his ideas on the information processing models of Neisser (1976) and Shiffrin and Schneider (1977), Magaro (1980) proposes a formulation which he claims is able to account for many of the differences between paranoid and nonparanoid schizophrenics both clinically and on laboratory tasks. A somewhat simplified discussion of this model therefore will be presented.
Figure 1. Simple information processing model (from Magaro, 1980, p.158)

Figure 1 shows a simplified flow chart of the information processing model used by Magaro (1980). As can be seen, the process begins with an external stimulus which creates an internal representation in the organism through an optical transformation. This "icon" lasts approximately one second in most experimental conditions, and is nothing more than a configuration of lines and colours of varying width, length and contrast.

There then follows two encoding processes which may operate sequentially or in a parallel either-or relationship. In Neisser's (1967) model the two processes involved in the encoding of the icon are preattentive processing and focal attention. Preattentive processing separates the iconic pattern into holistic parts, creating a figure from the field. The sequential focal-attention process acts upon this segment to begin the process of analysis of attributes in order to construct a percept from it. The two processes thus sequentially transform the image into attributes that can be categorized as an object. Keren (1976) has suggested that preattentive processing and focal attention are related to Broadbent's (1971) pigeonholing concept. One factor influencing iconic processing is perceptual set which biases the initial discrimination of information, giving preference to information of a particular perceptual character.

Schneider and Shiffrin (1977) have proposed the terms automatic and controlled processing, terms which parallel preattentive processing and focal attention.
They note that through repeated practice a sequence of memory nodes are formed that become activated by particular stimuli without the necessity of active control by the individual. At this stage the processing is automatic in that an element in the stimulus activates a cogit, the basic unit for further conceptualization. Automatic processing is "not limited by memory load or the number of distractors but only requires an initial discrimination of stimulus elements into sets that are practiced" (Magaro, 1980, p.163).

Controlled processing on the other hand is a sequential search operation which is limited by set size and memory load. Controlled processing, for example, is required in tasks which involve a serial comparison of a list of words in order to find a match. The subject attends to and controls the process, making extensive use of short-term memory storage to consider all matching possibilities. Automatic and controlled processing thus act in different types of situations depending upon past experiences and the degree of the categorization of the items searched.

The difference between the Neisser and Schneider and Shiffrin terms is whether one assumes segmenting is followed by a scrutiny of the segment, or whether the two processes are in parallel, that is, situation specific. Magaro attempts to resolve this difference by suggesting that preattentive processing itself involves prior experience because in order to separate the figure from the field one must have had previous experience of the figure.

The stage of processing following encoding is that of short term memory (figure 1). The encoding processes have acted upon the icon yielding a set of attributes. "Immediate memory is a short-term memory associational linkage, which provides the conceptual categories for translating attributes into recognizable forms (i.e. providing the name of a pattern)" (Magaro, 1980, p.160).

Just as perceptual set may influence what is segmented from the field at the preattentive process stage, a categorical set may bias what attributes are grouped to
define the object. For example, Bruner and Minturn (1955) presented the number 13. When subjects had been pretrained on letters they saw a B but when trained on numbers they accurately reported a 13. A perceptual set therefore influences the course of the preattentive process while a categorical set may influence the course of focal attention.

The simple conceptual categories formed by the associational linkage of attributes in short-term memory are known as "cogits" (Hayes-Roth, 1977). The cogit is activated in all-or-none fashion when the cogit is recognized in some external event. The greater the experience with a cogit the greater its strength and probability of being activated. Thus letters are formed into a word and after extensive usage the configuration of letters becomes unitized and memory of the word becomes activated in an all-or-none fashion.

A configuration of cogits is assembled by associations which follow the same laws as a cogit in that strength is determined by prior experience. A single cogit within such an assembly of associated cogits may be activated in all-or-none fashion by stimulating any element of the association. However the greater the complexity of the assembly the less the strength of the cogit configurations. Finally, an assembly itself can become a unit with all the properties of a cogit. This "functionally independent conceptual system" termed a schemata by Magaro, is also strengthened or weakened by experience and activated in an all-or-none fashion by stimuli that include only a part of the information in an assembly. Thus in Magaro's words:

"Information processing changes through learning when the elementary cogit is influenced by higher order assemblies and when higher order assemblies are modified by the introduction of new cogits. The information subsumed in a single cogit changes through experience and strengthens or weakens the assembly. As the strength of the cogit influences the strength of the assembly, so can the assembly modify the strength of the cogit. Thus, normal information processing is a two-way system with reciprocal effects among the schemata, the category, and the percept... This
constant interaction of percept and concept in deriving meaning is crucial to our understanding of information being derived from a constant dialectic, which cannot be accurately described if only one term is considered in isolation". (Magaro, 1980, p.162)

In Neisser's terms, "perceiving is a constructive process" (Neisser, 1967, p.95).

In Magaro's view then information flows in a circular movement where concept and percept interact, exploring the world of stimulation. Individual differences in "strategies" of information processing emphasize expectancies at different points in the flow. For example, individual differences may emerge in the proportional use of automatic or controlled processing. Long-term memory or schemata influence the perception or encoding of the stimulus when automatic processing is predominant; the priority of elements of the icon is established as in the perceptual set experiments, and the icon is perceived accordingly and automatically. The individual who relies upon controlled processing provides meaning by analysis of elements of the icon. However, if a particular category guides his search for the elements in similar but different fields he will come to the same conclusion. The validity of the category is immediately accepted and he enters into automatic processing. The category in such cases is sufficiently powerful for the world to be consistently perceived through such categorical sets. This may relate to Broadbent's (1971) concept of categorizing; in his terms it would represent a reliance on overly inclusive and global categories.

Magaro postulates that just such a situation occurs in paranoid schizophrenia. He sees the paranoid as consistently working backwards from the schemata to the icon while the schizophrenic (nonparanoid) works forwards. The paranoid reports what is mainly influenced by the schemata while the schizophrenic reports what is mainly received on the icon. The schizophrenic will tend to use the preattentive process predominantly, reporting global percepts or elementary concepts, though is able to employ
the nonpreferred controlled processing to produce a more detailed and accurate picture of the world if he is required to do so. However "the schizophrenic will be less adept at controlled processing, and even less so at automatic processing, if the situation is novel and he, thus, has to create the automatic processing categories" (Magaro, 1980, p.172). Magaro considers that the schizophrenic does not engage in the conceptual process, the forming of strong assemblies and schemata. Thus he hypothesizes that any task which relies upon such associated processes will show the greatest schizophrenic deficit. The difficulty for the schizophrenic is not at the initial organization of cogit configurations, where each cogit is identified with a discrete memory representation activated by an external stimulus, but at the stage where the initial associations are formed. The consequent assemblies would therefore be of low strength. "In effect there would be little "practice" of associating two cogits, the cogit configurations would never gain strength, and there would not be consistent conceptual categories or schemata" (Magaro, 1980, p.172).

By contrast, the paranoid will tend to use controlled processing. That is, information is processed in an active search with a reliance on the category. The paranoid will show the least deficit when using common assemblies or schemata, and provided they are not required to use many categories or contrasting schemata, their schemata strength should be greater than that of normals. The paranoid's categorical set works in such a way that his controlled processing is a biased search for specific attributes. At this point the paranoid also is able to use automatic processing and "once he is satisfied that the categories are established, he can automatically assign stimuli to these categories without much attention to the stimulus field... we hypothesize that the paranoid functions by consistently mapping the world with some words or faces as parts of a definite set. Automatic processing could thus result in an unusual perspective or a delusion" (Magaro, 1980, p.173).
A test of these ideas would thus require a task involving sufficient associations between stimuli and sufficient redundancy such that the paranoid has the basis and the time to establish categorical sets and move to automatic processing. Such processes may well be involved in the "illusory correlation" phenomenon.
5. ILLUSORY CORRELATIONS.

The term "illusory correlation" was coined by Chapman (1967) to describe the report by observers of a correlation between two events which in reality are (a) not correlated (b) correlated to a lesser extent than reported or (c) correlated in the opposite direction from that which is reported. Chapman considers racial and religious prejudice as well as the "halo effect" as examples of illusory correlations.

Chapman's first study on the subject sought to generate illusory correlations in the laboratory and to study the stimulus variables that influence it. His 163 subjects were presented with three series of pairs of words projected on a screen. At each presentation a single pair was shown for two seconds. Four possible words could appear on the left and three possible words on the right. All twelve possible pairs occurred with equal frequency and in random order. Two of the twelve word pairs had high associative strength (e.g. hat-head or knife-fork) while others had minimal associative connections (e.g. bread-foot). Chapman tested the effects on illusory correlation of (a) associative strength (b) distinctiveness of atypically long words (e.g. building-magazine) (c) the length of the series of word pairs and (d) the number of successive testings of such series.

Chapman's results showed that for each of the nine word pairs for which illusory correlations were predicted, the reported co-occurrence was greater than the correct value of 33 1/3 percent. Both pairs of words with high associative strength and pairs of long words were perceived by subjects to have been presented more often than other, low association pairs. Even the shortest series length of 48 (four presentations of each pair) produced strong illusory correlations. Over three successive testings however the strength of the illusory correlations declined.

Chapman and Chapman (1967, 1969, 1975) went on to note that, despite research evidence to the contrary, psychodiagnosticians were convinced on the basis of their clinical experience that projective tests such as the Rorschach and the Draw-a-Person Test were reliably related
to the personality characteristics of their patients. These authors found that the popular but invalid signs of the Rorschach had a strong verbal associative connection to the supposed symptoms. Using nearly seven hundred undergraduate subjects Chapman and Chapman (1969) showed that "naive" subjects "rediscovered" the same invalid Rorschach content signs even though these relationships were absent in the experimental materials. The misperception of clinical phenomena through illusory correlation has been investigated by several authors since Chapman and Chapman's pioneering work (e.g. Starr and Katkin 1969; Golding and Rorer, 1972). More recently use of the term has been extended to the study of impression formation (McArthur and Friedman, 1980) and stereotypic beliefs (Hamilton and Rose, 1980).

Among the various theoretical perspectives which might be used to account for illusory correlations are two which are worth examining (c.f. Hamilton and Rose, 1980). The first would be to explain illusory correlations in terms of an availability heuristic (Tversky and Kahneman, 1973) in which frequency judgements are based on the availability in memory of instances of the class of events being considered. One factor influencing availability would be the strength of the associative bond between the two events; the stronger the association the more available it is in memory and hence the more likely it will be overestimated in judgements of frequency of co-occurrence.

Schema theory (Rumelhart and Ortony, 1977) suggests an alternative interpretation, and is an approach with closer parallels to the Magaro model discussed above. According to this approach, knowledge is organized around generic concepts, represented in memory by schemas (schemata) which specify the constituents (assemblies) of a concept and the relationships (associations) that generally exist among them. "These schemas are used to select and organize incoming information with existing knowledge in memory, and retrieve it at a later point in time. Information is more likely to be comprehended and remembered when it is relevant to schema than when it is not" (Hamilton and Rose, 1980, p.843). Just as in the Magaro model,
schematic biases may influence attentional, organizational or retrieval processes, all of which are seen as cases of conceptually-driven or schema-driven top-down processing (Hamilton and Rose, 1980).

Since the paranoid is someone hypothesized to work backwards from the schemata to the icon and the non-paranoid schizophrenic is expected to work from the basis of the icon, making simple cogit configurations but failing to associate them into assemblies (Magaro, 1980), one would expect paranoid schizophrenics to make stronger illusory correlations and nonparanoid schizophrenics weaker illusory correlations than a matched group of normal subjects.
6. HYPOTHESES.

(1) It is hypothesized that when confronted with an experimental situation designed to elicit illusory correlations, paranoid schizophrenics will produce stronger illusory correlations than a matched group of normal subjects.

(2) It is further hypothesized that, given the same experimental conditions, nonparanoid schizophrenic will produce weaker illusory correlations than normal subjects.
B. METHOD.

1. Subjects.

The experimental subjects consisted of 19 inpatients (14 males, 5 females) from the Bethlem Royal and Maudsley joint teaching hospitals in southeast London, all with a current diagnosis of schizophrenia. Subjects were excluded if they (i) were younger than 17 or older than 60, (ii) had had E.C.T. within the past two months, or (iii) had been diagnosed as having organic impairment or a history of alcohol abuse.

The control group was composed of 10 normal subjects (8 males, 2 females) all employed by the hospitals. Each control subject was paid £2.00 for participation and was told that the experiment was a test of memory.

The patient group was divided into paranoid and nonparanoid groups on the basis of two scales designed to measure this distinction. The Maine Paranoid-Schizophrenic Rating Scale (Vojtisek, 1976) (appendix I) contains a scale for both constructs and was completed by the patient's doctor on the basis of interview and case notes. The other scale used was the Delusion Symptom-State Inventory (Bedford and Foulds, 1977) which is an 84-item self-report questionnaire given to the patient to complete. Three patients refused to complete the DSSI, ostensibly because of its length, and one patient had died before completing it. The difference between these two scales and their psychometric characteristics are discussed in Section A3 (pp.28). Using scores from these scales, three methods of dividing the patients into paranoid and nonparanoid groups was devised.

(a) Maine Scale (M1). Magaro (1980) suggests that subjects scoring more than or equal to 12 on the paranoid scale and less than or equal to 8 on the nonparanoid scale should be classified as paranoid; subjects scoring more than or equal to 10 on the nonparanoid scale and less than or equal to 6 on the paranoid scale should be classified as nonparanoid. Because such a division would
yield only four paranoid and no nonparanoid patients. We have modified the scoring cut-off points. We will classify patients who score more than or equal to 11 on the paranoid scale and less than or equal to 9 on the nonparanoid scale as paranoid patients, provided that a gap of at least four points exists between the two scores. All other patients will be considered nonparanoid. Such a division yields 7 paranoid and 12 nonparanoid patients.

(b) Maine Scale using a hierarchical model (M2). In Foulds' hierarchy of classes of personal illness (Foulds and Bedford, 1975) delusions of disintegration are viewed as the most profoundly disturbed symptoms, and a patient with these symptoms, according to his theory, is necessarily a member of all classes lower in the hierarchy. Thus, regardless of scores on less severe classes of illness, a patient with a disintegration score of greater than the cut-off is classified as (nonparanoid) schizophrenic. If this hierarchical model is applied to the scores from the Maine Scale and a cut-off of 9 or greater on the nonparanoid scale is used, there are 8 patients who will be classified as nonparanoid. We shall refer to the remainder as paranoid, though they represent simply a less disintegrated group than the nonparanoids.

(c) Delusion Symptom-State Inventory. As mentioned earlier, only 15 patients completed the DSSI. Using the recommended cut-off (Bedford and Foulds, 1978) of four or more for the disintegration scale there are 8 patients classified as nonparanoid. Of the remaining 7 patients only three scored four or more on the paranoid scale. Nonetheless, since the object of this division is to compare clearly nonparanoid (disintegrated) schizophrenics with other schizophrenics, all seven will be included in the paranoid group.

Measures of the process-reactive distinction were made using the Ullmann-Giovannoni self-report scale (Ullmann and Giovannoni, 1964). This scale is widely used for estimating premorbid social competence and is correlated with other indexes of premorbid status (McCreary, 1974).
Two indexes of chronicity were recorded from the patients' casenotes: months since first admission to a psychiatric hospital and months since present admission. Finally, both experimental and control groups were administered the Mill Hill Vocabulary Scale (Form 1 Senior) as a measure of intelligence.

**TABLE 1**

Descriptive Data on the Patient and Normal Groups

<table>
<thead>
<tr>
<th></th>
<th>Patients (N=19)</th>
<th>Normals (N=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean</strong></td>
<td><strong>SD</strong></td>
<td><strong>Mean</strong></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>30.10</td>
<td>8.58</td>
</tr>
<tr>
<td><strong>IQ</strong></td>
<td>91.58</td>
<td>7.32</td>
</tr>
<tr>
<td><strong>Process-Reactive Scale.</strong></td>
<td>10.52</td>
<td>2.7</td>
</tr>
<tr>
<td><strong>Months since first psychiatric admission.</strong></td>
<td>80.68</td>
<td>49.42</td>
</tr>
<tr>
<td><strong>Months since present admission.</strong></td>
<td>16.58</td>
<td>25.49</td>
</tr>
</tbody>
</table>

Since the schizophrenic group is to be divided in three different ways, descriptive data on the subgroups will be presented with the main body of results (Tables 3, 5, and 7). Table 1 shows these descriptive data for the normal group and the total schizophrenic group. There was no significant difference between the two groups in age or IQ.

2. **Apparatus.**

Four tasks were used in the present study. Each task involved the presentation of 12 pairs of stimuli of which four "A Stimuli" were paired with 3 "B Stimuli". Each of the stimulus pairs was presented four times
(i.e. equally often) but all were presented in random order, thereby making 48 random order presentations per task.

In the first three tasks stimulus pairs were presented on cards (5 inches by 8 inches), an A stimulus on the top and a B stimulus on the bottom. On the fourth task A stimuli were presented on cards while B stimuli were presented in the form of three electronically produced tones: (High pitch : 4,000 Hz/second; Low pitch : 800 Hz/sec; Intermittent (pulse) 650 Hz/sec; two quarter second pulses per second; output: approximately 75 db at 1 metre). All stimulus pairs were exposed for approximately two seconds each, with cards being presented above a screen between the experimenter and subject. On the experimenter's side of the screen were 12 slots, alphabetically labelled to correspond to the cards (see appendix 2). The experimenter presented the stimulus pairs according to one of 10 lists of 48 letters in random order.

All stimulus pairs were rated as to their strength of association by 22 subjects (mostly postgraduate students) not involved in the main experiment. These subjects were asked to rate on a five-point labelled scale ("1" representing the highest associative strength) the strength of the tendency for the first (A) stimulus to call to mind the second (B) stimulus. A copy of this questionnaire with the mean responses of the 22 subjects may be found in appendix 3.

Task 1. The first task involved the same stimuli used by Chapman (1967) in his first experimental demonstration of illusory correlations. Unlike Chapman's study however where stimulus pairs were presented horizontally (left-right), stimulus pairs in the present experiment were presented vertically (top-bottom). The stimuli (appendix 4a) were as follows:
As can be seen from the mean ratings of associative strength, Bacon-Eggs and Lion-Tiger were rated as being highly associated pairs. Ratings for all other stimulus pairs ranged from 4.36 to 5.00. In addition, Chapman found that the distinctiveness of atypically long words (i.e. Blossom-Notebook) also tended to produce illusory correlations.

**Task 2.**

<table>
<thead>
<tr>
<th>A Stimuli</th>
<th>B Stimuli</th>
<th>Associative Strength</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy</td>
<td>Happy</td>
<td>1.9</td>
</tr>
<tr>
<td>Sad</td>
<td>Sad</td>
<td>1.8</td>
</tr>
<tr>
<td>Angry</td>
<td>Angry</td>
<td>2.2</td>
</tr>
</tbody>
</table>

In this task (appendix 4b) three stimulus pairs were highly associated. All other stimulus pairs ranged from 3.4 to 4.8 in associative strength.

**Task 3.**

<table>
<thead>
<tr>
<th>A Stimuli</th>
<th>B Stimuli</th>
<th>Associative Strength</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secret</td>
<td>Spy</td>
<td>2.18</td>
</tr>
<tr>
<td>Victim</td>
<td>Killer</td>
<td>2.18</td>
</tr>
<tr>
<td>Envelope</td>
<td>Magazine</td>
<td>4.09</td>
</tr>
<tr>
<td>Clock</td>
<td>B Stimulus</td>
<td>4.82</td>
</tr>
</tbody>
</table>

The third task (appendix 4c) was similar to task 1 though an attempt was made to use words of possible relevance to individuals with paranoid delusions. It was speculated that the words secret, spy, victim and killer might have special significance to certain paranoids and therefore might be perceived to have been presented more often than nonsignificant words such as those in task 1. Secret-Spy and Victim-Killer were rated as having the highest associative strength and other stimulus pairs ranged from 3.00 (victim-spy) to 5.00 (clock-magazine).
Task 4.

A Stimuli: High
B Stimuli: pitch

High Stimuli: pitch
Intermittent
Any B stimulus

Associative Strength: 1.82 2.73 1.45 3.54

Other stimulus pairs ranged from 3.54 to 4.82.

This task (appendix 4d) involved two sensory modalities (visual and auditory) in order to examine the effects of attending to two sensory channels. High pitch, low pitch and intermittent tones were produced electronically and presented simultaneously with one of the four (A stimulus) cards. Broen (1973) has found that acute paranoids display broad sensitivity to environmental cues, unlike chronic nonparanoids who attenuate information from channels which are not of primary importance, thus appearing to monitor information from only one channel at a time. It was hoped that by using a task involving two sensory modalities, the tendency for nonparanoids to produce weaker illusory correlations than normals would be enhanced.

3. Procedure.

All subjects were tested alone in a quiet room, with subject and experimenter sitting at either side of a desk on which a screen was placed. Before any task was introduced six example cards were shown to subjects (appendix 5) in order to explain the nature of the tasks as well as to establish that the subject understood the concept of percentages. No standard instructions were given since subjects differed in the number of examples required before they had clearly understood what was required of them. However a typical explanation began:

"I'm going to show you a long series of cards in which each card has two things on it; something on the top and something on the bottom. Your job is to try to work out how often each of the top objects goes with each of the bottom objects. You'll be seeing too many cards to count them all, so don't try. Just try to form a general impression of what you see.

(Presenting two of the example cards)"For example here are two cards, both with a square on
the top and a different object on the bottom. If I showed you each card five times and asked you 'Of all the times you saw a square on the top what percentage of times did you see a hand on the bottom?' you would answer '50 per cent.'" (Adding a third card) "If there were three cards with squares on the top, what percentage of all the times that you saw a square on the top would you have seen a pair of scissors on the bottom?"

In this example, regardless of whether the subject answered 33 per cent, more examples would have been given. Adding a card with a circle on the top for example often confused subjects and it was therefore sometimes necessary to spend over ten minutes with these examples. Presentation of the experimental tasks began only when it became clear that the subject had understood what was required of him. The standard instructions before each task may be found in appendix 6.

Between tasks 2 and 3 subjects were administered the relevant questionnaires; both groups completed the Mill Hill Vocabulary Scale and the patient group additionally completed the process-reactive scale. At the end of testing the patients were given the DSSI and urged to complete it as soon as possible; most were returned within two days.

Testing usually lasted about seventy minutes for patients and fifty-five minutes for normals. During the presentation of tasks occasional observations were made to check that the subject was attending to the task. This was done by slightly moving the card being presented and checking for the subject's eye movement. On the basis of such observations it appeared that all subjects were attending adequately though some expressed fatigue at the end of testing.

After all 48 trials of each task had been presented the subject was handed a four page booklet in which he was required to rate the percentage frequency of each stimulus pair he had seen. Each page contained one of the A stimuli on the left (e.g. Bacon) and all three B stimuli on the right (e.g. Tiger, Eggs, Notebook) with empty boxes alongside each for the subject to write in
the percentages. The page orders of the booklets were randomized such that no two subjects received more than one of the four booklets in the same order. At this point the following instructions were given:

"Okay, that's the end of that task. Now take this little booklet and, looking at the word/figure on the left, try to remember as best you can what percentage of times this figure/word occurred with each of the three words/sounds on the right. (I shall play the three sounds for you again). Remember that the three numbers you write down on each page must add up to a hundred."

Three patients and one normal subject had shown by this point that they did not understand percentages though comprehended the nature of the task. These subjects were thus instructed to write down how many times, in absolute numbers, they thought they had seen each stimulus pair. These responses were later translated into percentages by the experimenter.

The correct co-occurrence for every stimulus pair in each task was of course 33\(\frac{1}{3}\) per cent. Any two stimuli reported to have co-occurred with a higher frequency than 33\(\frac{1}{3}\) per cent therefore will have been illusorily correlated.
C. RESULTS.

1. The Assessment of Paranoid-Nonparanoid Status.

|          | Paranoid | Nonparanoid | Paranoid | Disintegration | Nonparanoid | Disintegration | Table 2 shows the correlations between the subscales of the Maine Scale and the DSSI (N=15). |
|----------|----------|-------------|----------|----------------|-------------|----------------|.........................................................................................................................|
| Maine Scale |          |             |          |                |             |                | Table 2 shows the correlations between the subscales of the Maine Scale and the Delusion Symptom-State Inventory based on data from the fifteen patients who completed the DSSI and the nineteen on whom a Maine Scale was completed. Although the paranoid subscale of the Maine Scale was significantly correlated with the corresponding subscale of the DSSI there was merely a nonsignificant but positive correlation between the nonparanoid subscale of the Maine Scale and the disintegration (nonparanoid) subscale of the DSSI. Moreover, the disintegration subscale of the DSSI correlated more highly with the paranoid subscale than the nonparanoid subscale of the Maine Scale, and similarly, the nonparanoid subscale of the Maine Scale correlated significantly with the paranoid subscale of the DSSI but not with the disintegration subscale. Interestingly, the two subscales of both instruments correlated positively with each other, indicating that a high score on one subscale tended to occur with a high score on the other subscale. While this correlation was relatively
small between the subscales of the Maine Scale it was highly significant between the subscales of the DSSI.

The relationship between the three methods used in this study to assign schizophrenics to paranoid and non-paranoid groups was examined using the kappa coefficient which takes into account the expected agreements that would occur by chance alone when allocating subjects to different categories. Comparing the assignment of patients according to the allocation methods defined above it was found that M1 (based upon both subscales of the Maine Scale) and M2 (the Maine Scale using scoring methods consistent with a hierarchical model) showed a low level of agreement (k=0.19). M1 also related poorly to allocations made by the DSSI (k=0.18). Finally M2 yielded the lowest agreement among the three methods when it was compared with the DSSI (k=0.07) which itself originates from a hierarchical model (Foulds and Bedford, 1975). Thus, the three methods of allocating patients to paranoid and nonparanoid categories were poorly related to one another.

2. Illusory Correlations.

Results are presented according to the three methods by which the schizophrenic group was divided into paranoid and nonparanoid groups.

(a) Maine Scale (M1).

### TABLE 3

Descriptive data for the paranoid, nonparanoid and normal groups according to allocations made by the Maine Scale (M1).

<table>
<thead>
<tr>
<th></th>
<th>Paranoinds N=7</th>
<th>Nonparanoinds N=12</th>
<th>Normals N=10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean S.D.</td>
<td>Mean S.D.</td>
<td>Mean S.D.</td>
</tr>
<tr>
<td>Age</td>
<td>36.0 9.99</td>
<td>26.66 5.94</td>
<td>28.7 10.85</td>
</tr>
<tr>
<td>Mill Hill I.Q.</td>
<td>91.0 9.92</td>
<td>91.9 8.26</td>
<td>92.8 9.95</td>
</tr>
<tr>
<td>Maine Paranoid Scale</td>
<td>13.6 1.8</td>
<td>9.5 3.58</td>
<td></td>
</tr>
<tr>
<td>Maine Nonparanoid Scale</td>
<td>7.1 1.57</td>
<td>10.42 3.96</td>
<td></td>
</tr>
<tr>
<td>DSSI Paranoid Scale</td>
<td>5.4 3.21</td>
<td>4.9 6.49</td>
<td></td>
</tr>
<tr>
<td>DSSI Disintegration Scale</td>
<td>6.6 4.98</td>
<td>5.6 4.83</td>
<td></td>
</tr>
<tr>
<td>Chronicity 1 (in months)</td>
<td>101.6 19.8</td>
<td>68.5 57.8</td>
<td></td>
</tr>
<tr>
<td>Chronicity 2 (in months)</td>
<td>20.4 24.6</td>
<td>14.3 26.8</td>
<td></td>
</tr>
<tr>
<td>Process-Reactive Scale</td>
<td>11.0 3.37</td>
<td>10.25 2.49</td>
<td></td>
</tr>
</tbody>
</table>

© Chronicity 1 refers to months since first admission. Chronicity 2 refers to months since present admission.
Table 3 shows descriptive data for the paranoid, non-paranoid and normal groups divided according to allocations made on the basis of both subscales of the Maine Scale, the method we have referred to as M1. The paranoid group was found to be significantly older ($t=2.64; p<0.02$) than the nonparanoid group but not the normal group. As one might expect from the nature of this scoring method, the paranoid group scored significantly higher ($t=2.81; p<0.02$) on the paranoid subscale of the Maine Scale than did the non-paranoid group. There were no other statistically significant differences between the groups.

### TABLE 4
Mean frequency estimates of critical stimulus pairs for the paranoid, nonparanoid and normal groups according to allocations made by the Maine Scale (M1).

<table>
<thead>
<tr>
<th>Task No</th>
<th>Stimulus Pair</th>
<th>Paranoids</th>
<th>Nonparanoids</th>
<th>Normals</th>
<th>Response $X^*$</th>
<th>Group $X^*$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(A)</td>
<td>(B)</td>
<td>$(N=7)$</td>
<td>$(N=12)$</td>
<td>$F = \</td>
<td>p =$</td>
</tr>
<tr>
<td>1(a)</td>
<td>BACON - EGGS</td>
<td>55.6</td>
<td>49.0</td>
<td>47.8</td>
<td>12.180</td>
<td>0.002</td>
</tr>
<tr>
<td>1(b)</td>
<td>LION - TIGER</td>
<td>26.7</td>
<td>40.2</td>
<td>36.6</td>
<td>0.384</td>
<td>0.591</td>
</tr>
<tr>
<td>1(c)</td>
<td>BLOSSOM - NOTEBOOK</td>
<td>38.4</td>
<td>36.5</td>
<td>35.2</td>
<td>1.145</td>
<td>0.254</td>
</tr>
<tr>
<td>2(a)</td>
<td>HAPPY</td>
<td>38.0</td>
<td>34.8</td>
<td>37.8</td>
<td>1.500</td>
<td>0.232</td>
</tr>
<tr>
<td>2(b)</td>
<td>SAD</td>
<td>33.7</td>
<td>41.8</td>
<td>38.1</td>
<td>2.450</td>
<td>0.129</td>
</tr>
<tr>
<td>2(c)</td>
<td>ANGRY</td>
<td>29.1</td>
<td>34.9</td>
<td>41.8</td>
<td>0.747</td>
<td>0.395</td>
</tr>
<tr>
<td>3(a)</td>
<td>VICTIM - KILLER</td>
<td>34.1</td>
<td>40.2</td>
<td>43.2</td>
<td>2.639</td>
<td>0.116</td>
</tr>
<tr>
<td>3(b)</td>
<td>SECRET - SPY</td>
<td>49.1</td>
<td>45.0</td>
<td>35.9</td>
<td>6.819</td>
<td>0.015</td>
</tr>
<tr>
<td>3(c)</td>
<td>ENVELOPE-MAGAZINE</td>
<td>42.0</td>
<td>39.0</td>
<td>42.8</td>
<td>3.850</td>
<td>0.061</td>
</tr>
<tr>
<td>4(a)</td>
<td>Intermittent</td>
<td>53.7</td>
<td>39.2</td>
<td>35.1</td>
<td>5.830</td>
<td>0.023</td>
</tr>
<tr>
<td>4(b)</td>
<td>High pitch</td>
<td>35.4</td>
<td>37.6</td>
<td>42.0</td>
<td>3.192</td>
<td>0.086</td>
</tr>
<tr>
<td>4(c)</td>
<td>Low pitch</td>
<td>34.9</td>
<td>36.8</td>
<td>39.3</td>
<td>1.590</td>
<td>0.218</td>
</tr>
</tbody>
</table>

**Mean**: 39.22 39.58 39.63 * d.f. = 1,26.

Table 4 shows the mean frequency estimates of the stimulus pairs for which illusory correlations were predicted (i.e. high in associative strength or atypically long words). The groups are divided according to allocations made by the Maine Scale using our modified scoring criteria.
Results were analysed using a repeated measures analysis of variance of the critical response (the stimulus pair for which an illusory correlation was predicted - e.g. bacon-eggs) versus the mean of the other two possible responses (bacon-tiger, bacon-notebook). The group by response interaction was also examined.

Table 4 shows impressively that all groups made illusory correlations (i.e. a response greater than 33.3%) in the predicted stimulus pairs. On only two frequency estimates did a group not respond with illusory correlations; the paranoid group underestimated the frequency of stimulus pairs 1(b) and 2 (c), illusorily correlating instead Lion-Eggs (40.71%) and the figure of stimulus pair 2 (c) with Sad (44.71%).

Three stimulus pairs (1(a), 3(b) and 4(a)), were found to be significantly different from their other possible responses across all groups, and on all three occasions the paranoid group had the highest mean. There were no significant results for the group X response interaction.

On only half of the twelve critical responses did the paranoid group obtain a higher mean than the nonparanoid group and on only six of the critical responses did the nonparanoids obtain lower means than the normals. Indeed the average mean for all critical responses across all tasks was the same for all groups (paranoid: 39.22%; nonparanoid: 39.58%; normal: 39.63%). Thus, according to this division of the patients there was little overall difference between the groups in their tendency to make illusory correlations. There was also no apparent trend for differential tendencies for groups to make stronger illusory correlations on some tasks than others.

(b) Maine Scale using a hierarchical model (M2).

Table 5, below, shows descriptive data for the three groups divided according to the Maine Scale using a scoring method consistent with a hierarchical model (M2). Patients obtaining a score of 9 or greater on the nonparanoid subscale of the Maine Scale were classified as non-paranoid and the remainder were classified as paranoid.
TABLE 5

Descriptive data for the paranoid, nonparanoid and normal groups according to allocations made by the Maine Scale scored according to a hierarchical model (M2).

<table>
<thead>
<tr>
<th></th>
<th>Paranoids N = 11 (M=8, P=3)</th>
<th>Nonparanoids N = 8 (M=6, P=2)</th>
<th>Normals N = 20 (M=8, P=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
</tr>
<tr>
<td>Age</td>
<td>32.45</td>
<td>8.64</td>
<td>26.87</td>
</tr>
<tr>
<td>Mill Hill I.Q.</td>
<td>90.09</td>
<td>7.31</td>
<td>93.62</td>
</tr>
<tr>
<td>Maine Paranoid Scale</td>
<td>10.27</td>
<td>3.66</td>
<td>12.0</td>
</tr>
<tr>
<td>Maine Nonparanoid Scale</td>
<td>6.73</td>
<td>1.10</td>
<td>12.62</td>
</tr>
<tr>
<td>DSSI Paranoid Scale</td>
<td>2.87</td>
<td>3.72</td>
<td>7.57</td>
</tr>
<tr>
<td>DSSI Disintegration Scale</td>
<td>4.75</td>
<td>4.95</td>
<td>7.28</td>
</tr>
<tr>
<td>Chronicity 1. (in months)</td>
<td>174.45</td>
<td>47.40</td>
<td>89.25</td>
</tr>
<tr>
<td>Chronicity 2. (in months)</td>
<td>20.54</td>
<td>26.78</td>
<td>11.12</td>
</tr>
<tr>
<td>Process-Reactive Scale</td>
<td>10.82</td>
<td>3.12</td>
<td>10.12</td>
</tr>
</tbody>
</table>

Not surprisingly the group of patients classified as nonparanoid by this method obtained significantly higher (t=6.08; p<0.01) scores on the nonparanoid subscale of the Maine Scale than the paranoid group. The three groups did not differ significantly on any other independent variable.

Table 6, below, shows the mean frequency estimates of the critical stimulus pairs for the three groups divided according to allocations made by the M2 method. While all groups made illusory correlations only three responses (1(a), 3(b) and 4(a)) were statistically different from the means of the other two possible stimulus pairs.

The paranoid group made illusory correlations on only six of the twelve stimulus pairs for which they were predicted. The paranoids by contrast made illusory correlations on ten stimulus pairs and normals made them on all twelve. Two group X response interactions (3(a) and 3(b)) attained statistical significance and another (2(a)) approached significance. On all three the paranoid group made stronger illusory correlations than the other two groups.

The paranoid group made stronger illusory correlations than nonparanoids on six of the twelve critical stimulus pairs. On all occasions that the nonparanoid group made
TABLE 6

Mean frequency estimates of critical stimulus pairs for the paranoid, nonparanoid and normal groups according to allocations made by M2.

<table>
<thead>
<tr>
<th>Task No</th>
<th>Stimulus Pair</th>
<th>Paranoids (N = 11)</th>
<th>Nonparanoids (N = 8)</th>
<th>Normals (N = 10)</th>
<th>Response X Response *</th>
<th>Group X Response *</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td>BACON - EGGS</td>
<td>51.09</td>
<td>51.87</td>
<td>47.8</td>
<td>12.180</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b)</td>
<td>LION - TIGER</td>
<td>37.27</td>
<td>32.37</td>
<td>36.6</td>
<td>0.384</td>
<td>0.541</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c)</td>
<td>BLOSSOM - NOTEBOOK</td>
<td>35.36</td>
<td>39.75</td>
<td>35.2</td>
<td>1.145</td>
<td>0.294</td>
</tr>
<tr>
<td>1</td>
<td>(a) HAPPY</td>
<td>43.09</td>
<td>26.25</td>
<td>37.8</td>
<td>1.500</td>
<td>0.232</td>
</tr>
<tr>
<td>2</td>
<td>(b) SAD</td>
<td>43.27</td>
<td>32.6</td>
<td>38.1</td>
<td>2.450</td>
<td>0.129</td>
</tr>
<tr>
<td></td>
<td>(c) ANGRY</td>
<td>29.27</td>
<td>37.6</td>
<td>41.8</td>
<td>0.747</td>
<td>0.395</td>
</tr>
<tr>
<td>3</td>
<td>(a) VICTIM - KILLER</td>
<td>49.0</td>
<td>22.87</td>
<td>43.2</td>
<td>2.639</td>
<td>0.116</td>
</tr>
<tr>
<td></td>
<td>(b) SECRET - SPY</td>
<td>56.27</td>
<td>33.12</td>
<td>35.9</td>
<td>6.819</td>
<td>0.015</td>
</tr>
<tr>
<td></td>
<td>(c) ENVELOPE - MAGAZINE</td>
<td>47.0</td>
<td>30.6</td>
<td>42.8</td>
<td>3.850</td>
<td>0.061</td>
</tr>
<tr>
<td>4</td>
<td>(a)</td>
<td>44.45</td>
<td>44.75</td>
<td>35.1</td>
<td>5.830</td>
<td>0.023</td>
</tr>
<tr>
<td></td>
<td>intermittent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(b) High pitch</td>
<td>35.73</td>
<td>38.25</td>
<td>42.0</td>
<td>3.192</td>
<td>0.086</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(c) Low pitch</td>
<td>32.9</td>
<td>40.5</td>
<td>39.3</td>
<td>1.590</td>
<td>0.218</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>42.06</td>
<td>35.87</td>
<td>39.63</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* d.f. = 1.26.

Illusory correlations they were stronger than those of the paranoid group. On nine responses the paranoid group made stronger illusory correlations than the normals and on eight responses the nonparanoid group made weaker illusory correlations than the normals. Furthermore, when the means of the group means were calculated the paranoid group showed the strongest overall tendency to make illusory correlations (42.06%) and the nonparanoids group the weakest tendency (35.87%) a figure approaching 33.3% which represents reality and a failure to consistently make illusory correlations on the predicted stimulus pairs. The normal group's overall mean frequency estimate across all critical responses was 39.63% which falls, as predicted, between the two groups. However because these average group means contain considerable variance they are not different to a statistically significant extent.

Two illusory correlations, which we shall term idiosyncratic because they were not made on the predicted stimulus
pairs, are worth mentioning. The nonparanoid group illusorily correlated the A-stimulus of stimulus pair 2(a) with Angry (44.75%) rather than Happy. The other idiosyncratic illusory correlation was made by the paranoid group which on task 2(c) reported having observed the A-stimulus with Sad (46.45%) rather than the predicted Angry.

Finally there was a strong tendency for the paranoid group to make stronger illusory correlations than other groups on task 3. It will be recalled that task 3 was devised with the object of including words of particular relevance to paranoid patients. However there was no tendency for the nonparanoid group to make weaker illusory correlations on task 4 as had been predicted for a task involving two sensory modalities.

(c) Delusion Symptom-State Inventory.

<table>
<thead>
<tr>
<th>TABLE 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptive data for the paranoid, nonparanoid and normal groups according to allocation made by the DSSI.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Paranoids (N = 7, F=2)</th>
<th>Nonparanoids (N = 8, F=1)</th>
<th>Normals (N = 10, F=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
</tr>
<tr>
<td></td>
<td>10.0</td>
<td>6.85</td>
<td>29.12</td>
</tr>
<tr>
<td>Mill Hill I.Q.</td>
<td>92.29</td>
<td>5.91</td>
<td>92.12</td>
</tr>
<tr>
<td>Maine Paranoid Scale</td>
<td>9.43</td>
<td>3.91</td>
<td>11.87</td>
</tr>
<tr>
<td>Maine Nonparanoid Scale</td>
<td>8.14</td>
<td>1.86</td>
<td>10.37</td>
</tr>
<tr>
<td>DSSI Paranoid Scale</td>
<td>2.43</td>
<td>2.88</td>
<td>7.37</td>
</tr>
<tr>
<td>DSSI Disintegration Scale</td>
<td>1.86</td>
<td>1.46</td>
<td>9.50</td>
</tr>
<tr>
<td>Chronicity 1. (in months)</td>
<td>13.43</td>
<td>46.5</td>
<td>80.75</td>
</tr>
<tr>
<td>Chronicity 2. (in months)</td>
<td>3.43</td>
<td>2.82</td>
<td>17.62</td>
</tr>
<tr>
<td>Process-Reactive Scale</td>
<td>11.86</td>
<td>2.34</td>
<td>9.87</td>
</tr>
</tbody>
</table>

Table 7 presents descriptive data for the three groups divided according to allocations made by the DSSI. Since any patient scoring four or more on the disintegration subscale of the DSSI was assigned to the nonparanoid group it is therefore not surprising that this group obtained a significantly higher \((t=5.47; \ p<0.01)\) mean score than the paranoid group on the disintegration subscale. There were no other statistically significant differences between the groups.
### Table 8

Mean frequency estimates of critical stimulus pairs for the paranoid, nonparanoid and normal groups according to allocations made by the DSSI.

<table>
<thead>
<tr>
<th>Task No</th>
<th>Stimulus Pair (A) - (B)</th>
<th>Paranoids (N = 7)</th>
<th>Nonparanoids (N = 8)</th>
<th>Normals (N = 10)</th>
<th>Response X *</th>
<th>Group X Response F = p =</th>
<th>p =</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(a)</td>
<td>BACON - EGGS</td>
<td>51.0</td>
<td>49.0</td>
<td>47.8</td>
<td>9.318</td>
<td>0.006</td>
<td>0.032</td>
</tr>
<tr>
<td>1(b)</td>
<td>LION - TIGER</td>
<td>31.0</td>
<td>45.5</td>
<td>36.6</td>
<td>1.279</td>
<td>0.270</td>
<td>0.982</td>
</tr>
<tr>
<td>1(c)</td>
<td>BLOSSOM - NOTEBOOK</td>
<td>31.7</td>
<td>42.1</td>
<td>35.2</td>
<td>1.357</td>
<td>0.257</td>
<td>1.076</td>
</tr>
<tr>
<td>2(a)</td>
<td>- HAPPY</td>
<td>34.3</td>
<td>38.6</td>
<td>37.8</td>
<td>1.710</td>
<td>0.204</td>
<td>0.184</td>
</tr>
<tr>
<td>2(b)</td>
<td>- SAD</td>
<td>48.6</td>
<td>33.2</td>
<td>38.1</td>
<td>3.313</td>
<td>0.082</td>
<td>1.532</td>
</tr>
<tr>
<td>2(c)</td>
<td>- ANGRY</td>
<td>33.6</td>
<td>43.0</td>
<td>41.8</td>
<td>7.418</td>
<td>0.012</td>
<td>1.305</td>
</tr>
<tr>
<td>3(a)</td>
<td>VICTIM - KILLER</td>
<td>43.0</td>
<td>30.0</td>
<td>41.2</td>
<td>1.928</td>
<td>0.178</td>
<td>1.124</td>
</tr>
<tr>
<td>3(b)</td>
<td>SECRET - SPY</td>
<td>46.1</td>
<td>33.7</td>
<td>35.9</td>
<td>2.667</td>
<td>0.117</td>
<td>1.530</td>
</tr>
<tr>
<td>3(c)</td>
<td>ENVELOPE - MAGAZINE</td>
<td>32.7</td>
<td>39.5</td>
<td>42.8</td>
<td>2.113</td>
<td>0.160</td>
<td>0.556</td>
</tr>
<tr>
<td>4(a)</td>
<td>- Intermittent</td>
<td>40.0</td>
<td>45.4</td>
<td>35.1</td>
<td>10.200</td>
<td>0.004</td>
<td>1.929</td>
</tr>
<tr>
<td>4(b)</td>
<td>- High pitch</td>
<td>33.8</td>
<td>40.6</td>
<td>42.0</td>
<td>4.120</td>
<td>0.055</td>
<td>0.653</td>
</tr>
<tr>
<td>4(c)</td>
<td>- Low pitch</td>
<td>37.4</td>
<td>39.2</td>
<td>39.3</td>
<td>3.219</td>
<td>0.087</td>
<td>0.034</td>
</tr>
</tbody>
</table>

| Mean:   | 38.60                  | 39.98             | 39.63               |

* d.f. = 1,22.

Table 8 presents the mean frequency estimates of the critical stimulus pairs for the three groups divided according to allocations made by scores on the disintegration subscale of the DSSI. While the majority of critical responses for all three groups represented illusory correlations, the paranoid group made only nine while the nonparanoid and normal groups made ten and twelve respectively. Three critical responses (1(a), 2(c) and 4(a)), were statistically different from their alternatives at the 0.05 level of significance.

On eight of the twelve critical responses the nonparanoid group made stronger illusory correlations than the paranoid groups though the average of their mean frequency estimates (39.98%) was only fractionally higher
than that of the paranoid group (38.6%) and very similar to that of the normal group (39.63%). On six critical responses the nonparanoid group made stronger illusory correlations than the normal group.

Finally, there was some tendency for the nonparanoid group to make stronger illusory correlations than the paranoid group on tasks 1 and 4. There was also a tendency for the paranoid group to make stronger illusory correlations than the nonparanoid group on task 3 which includes stimuli of possible relevance to paranoid patients.
D. DISCUSSION.

1. The Assessment of Paranoid-Nonparanoid Status.

Although the subscales of the Maine Scale correlated positively with the corresponding subscales of the DSSI, they also correlated positively with the other subscales. This was largely due to the fact that the subscales of the DSSI correlated extremely highly with each other (r=0.86).

The high intercorrelation of the paranoid and disintegration scales of the DSSI suggests that either the patients were poorly differentiated on this dimension or that the DSSI poorly discriminates patients according to this dimension. With regard to the latter notion it seems plausible that some patients may have completed the DSSI with a positive response set (i.e. responding true to most items) while others, perhaps paranoids, may have responded with a negative response set (i.e. denying most items).

Since the DSSI lacks a lie scale it is impossible to answer this question with the present data.

The intercorrelation of the subscales of the Maine Scale was relatively low (r=0.20) and using our modification of its scoring methods (M1) this scale differentiated patients into two distinct groups. It was also based upon a psychiatrist's assessment of the patient's mental state rather than the self-report of the patient. Since the DSSI lacks both a lie scale and reliability data and relies upon the patient's own report it would seem advisable to place greater reliance on data generated from the Maine Scale than data from the DSSI.

On the whole the two instruments were poorly related to one another. This finding is therefore at odds with those of Magaro et al (1981) in as far as they reported a high association between the subscales of the Maine Scale and the corresponding subscales of the original SSI. In the present study there were not only sizable correlations between the paranoid subscale of one instrument and the non-paranoid or disintegration scale of the other instrument but allocations made by the two scales related poorly to
one another, albeit using modified scoring procedures. It must be stressed that of the three methods of allocation used in the present study only M1 generated groups of paranoid and nonparanoid patients. The DSSI and M2 both assigned patients to a group of disorganized or disintegrated non-paranoids and a group of less disorganized or less dis-integrated patients, whether they were paranoid or not.

Of particular interest was the lack of any relationship between the two methods of allocation using a hierarchical model of illness, M2 and DSSI. It appears from our data that the nonparanoid subscale of the Maine Scale measures a different construct from that being measured by the dis-integration subscale of the DSSI. Again, since the DSSI is both of unknown reliability and is a self-report measure one must give more weight to the M2 division of patients into nonparanoid and nondisintegrated groups.

Returning to Berkowitz's (1981) criticisms of the use of the paranoid-nonparanoid distinction it may be said that neither scale identified two distinct groups when orthodox scoring procedures were employed; most patients failed to qualify for either group. The DSSI in particular appeared to be a poor discriminator of the dimension and in as far as it relies upon self-report and lacks both a lie scale and reliability data, its usefulness appears limited for the purpose in question. The Maine Scale however did identify groups of paranoid and nonparanoid patients after its scoring criteria had been modified. It also discriminated a group of nonparanoids and a group of nondisintegrated patients. However it remains to be seen what clinical or other correlates exist to justify these allocation methods in terms of their clinical or research usefulness.

2. Illusory Correlations.

Regardless of the method of dividing patients into paranoid and nonparanoid groups, the results of this study convincingly demonstrate the illusory correlation phenomenon, thus confirming the findings of Chapman (1967). All groups made illusory correlations on the majority of predicted stimulus pairs of all tasks.

Perhaps inherent in any task designed to generate illusory correlations is an expectation on the part of the
subject that stimulus pairs will not occur with equal frequency. However it is unlikely that a task could be devised which eradicates this expectation. Moreover, several subjects reported that they were aware that certain stimulus pairs were highly associated and thereafter attempted not to be influenced by this observation. They nonetheless reported having observed these stimulus pairs with a higher frequency than other stimulus pairs, attesting to the strength of the illusory correlation phenomenon.

Among all the analyses of variance performed on the data there were very few statistically significant results. However, given the small numbers in each group this lack of significant results is perhaps not surprising.

Dividing the schizophrenic group according to the Maine Scale (Ml) did not yield any consistent differences between the groups in the strength of the illusory correlations they produced. It will be recalled that this method of dividing patients was the only one which ostensibly produced paranoid and nonparanoid groups. Thus, this method of allocation afforded no support for the experimental hypotheses.

The DSSI method of allocation to groups of disintegrated and nondisintegrated patients also yielded few differences between groups. Overall group means (across all tasks) were within one and a half percentage points of one another and of these the paranoid group had the lowest overall mean. There was a predicted tendency for the paranoid group to make stronger illusory correlations on task 3 which was designed to include words of relevance to paranoid patients. However on tasks 1 and 4 the nonparanoid group tended to make stronger illusory correlations than the paranoid group. It had been predicted that nonparanoids would make weaker associations between associated stimuli when two stimuli were of different sensory modalities such as task 4. Clearly there was no support in the present study for such an hypothesis.

The only division of the schizophrenic group which produced any notable differences between groups was that which allocated patients according to scores on the nonparanoid subscale of the Maine Scale. This method of allocation
(M2) produced predominantly nonsignificant trends in the predicted directions. Although there was considerable variance across responses, the paranoid group's overall mean was 6.19 percentage points higher than that of the nonparanoid group. Also, as predicted, there was a tendency for the nonparanoid group to produce weaker illusory correlations than the normal group. Moreover, the nonparanoid group made illusory correlations on only six of the twelve predicted stimulus pairs, though on all six they made stronger illusory correlations than those of the paranoid group. An interesting further examination would be to determine which items of the Maine Scale were responsible for the greatest part of the variance of the main effect (illusory correlations).

Again there was a notable tendency for the paranoid group to make particularly strong illusory correlations on task 3 which involved stimuli relevance to patients with paranoid delusions. This is a curious finding when one considers that on both occasions in which it occurs the methods of allocation used (M2 and DSSI) did not produce groups of paranoid patients but groups of nondisintegrated patients, only some of whom scored highly on the paranoid subscales. However, the strength of this tendency for paranoid-relevant words to elicit stronger illusory correlations in paranoids than in nonparanoids suggests that the paranoid group formed, or already held, strong schemata with which to categorize these stimuli. This finding is not inconsistent with those of Schneider (1976) who compared the performances of groups of patients on dichotic shadowing tasks under different conditions. He found that when distraction material pertained to the particular delusions of individual delusional schizophrenics, the patients' shadowing performance was more impaired than when the distraction material was of a more neutral nature (i.e. physics). He concluded that his evidence suggests that "some of the memory traces that delusional schizophrenics judge as relevant are seldom judged as relevant by normals" (Schneider, 1976, p 172).
To summarize, when patients were allocated according to M1 or the DSSI there were negligible group differences on the mean strength of their illusory correlations. When patients were allocated to non-paranoid and nondisintegrated groups according to M2, the nondisintegrated group tended to make stronger illusory correlations on average than the nonparanoid group. While this result may represent little more than a chance finding it remains the only notable difference between the groups and is consistent with our hypotheses. The nondisintegrated group thus appeared to perform in the fashion in which paranoids would be expected to perform according to Magaro's (1980) views; having established categories or schemata with which to organize incoming stimuli they moved to automatic processing whereby they automatically assigned most stimuli to these categories without much attention to the stimulus field.

The nonparanoids by contrast made illusory correlations on only six of the twelve predicted stimulus pairs. Thus they failed to establish categories with which to process these high association stimulus pairs. Again this finding is consistent with our main hypothesis and Magaro's view that in nonparanoids "there would be little 'practice' of associating two cogs, the cogit configurations would never gain strength, and there would not be consistent conceptual categories or schemata" (Magaro, 1980, p.172).

The results thus suggest that paranoids recalled the information presented with an exaggerated response bias. Broadbent (1971) has pointed out that processes of retrieval from memory involve such strategies of selection: "Just as in perception, selection may be through the choice of all items possessing a particular feature; or it may be by the setting up of an output vocabulary only members of which will be used, and which should be distinguished by complex combinations of features. The first is a filtering mechanism; the latter corresponds to pigeon-holing in perception" (Broadbent, 1971, p.339). The argument therefore is that paranoids may be expected to show exaggerated response biases in recall, resulting in
stronger illusory correlations. In other words their response bias towards the Bacon-Eggs stimulus pair would be stronger than that towards Bacon-Tiger or Bacon-Notebook.

In Hemsley's (1977) terms the approximation strategy is used predominantly by paranoids and normals to adapt and "make sense of" the large quantities of information involved in each task. The more disintegrated nonparanoids are less adept at employing this strategy and thus perceive less order in the information presented. However it is important to stress that if this M2 division of patients has in fact identified different subgroups of schizophrenia they may differ only in as far as they are characterized by these different cognitive strategies of adaptation. Furthermore this division of schizophrenia is only useful in as far as it has other, practical correlates.

Our findings are not inconsistent with the somewhat different perspective of Radley (1974) who has reviewed research into the personal constructs of schizophrenics. He noted that paranoid (non-thought-disordered) schizophrenics have been found to have relatively tight constructs which are invariable in Intensity (referred to as cognitive simplicity). In perceiving another person the cognitively simple person may not only form successive, contrasting impressions but he may attempt a resolution of the incompatibility by construing the problematic individual in only one of the contrasting roles. Bannister (1962) found that non-thought disordered schizophrenics tend to allocate elements at one pole rather than the contrast on each construct dimension. Radley suggests that this may reflect an attempt by the individual to establish a coherent impression of the person by focusing on one aspect of his behaviour and ignoring evidence to the contrary. "This strategy of construing is one in which the person is actively seeking validation for his chosen construction [category, schemata], while simultaneously avoiding evidence supportive of the contrasting construction". (Radley, 1974, p.322).

Several shortcomings of this study warrant discussion. Firstly, as has been mentioned before, the study lacked sufficient numbers of subjects within groups in order for clear differences between groups to emerge. It is likely that larger groups of subjects would reflect any differences more clearly. Secondly, and perhaps more importantly,
neither diagnostic instrument used, generated clearly differentiated groups of paranoid and nonparanoid subjects from the nineteen patients, when orthodox scoring methods were applied. Only after the cut-offs for the Maine Scale had been altered (M1) were there groups of paranoid and nonparanoid patients. The other two methods generated a group of disintegrated or nonparanoid patients and a group of nondisintegrated schizophrenic patients.

A future study examining illusory correlations with patient groups might do well to avoid the use of percentages by subjects reporting frequency estimates. For many subjects percentages were a familiar concept but not one which they habitually employed. A possible result of this was the fact that many subjects became "stuck" in a response pattern (e.g. always responding with 50%, 30%, and 20% in various orders) since this requires less effort than working out the percentages to accurately reflect one's perception of the frequency of stimulus pairs. This stereotyped responding on the other hand may also be reflecting a tendency to use simplified categorizing such as was demonstrated in Koh and Shears' (1970) study, discussed in section A2(b). In future research the use of absolute numbers, which later may be converted into percentages, may be a more appropriate method of obtaining frequency estimates.

Another methodological criticism which may be levelled against the present study is the lack of control over exposure time for each stimulus pair. Although an effort was made by the experimenter to maintain the same exposure time for all stimulus pairs (i.e. the experimenter used covert counting to pace himself), an electronically time-controlled method of presentation, such as a timed slide projector would have been preferable. Furthermore the experimenter was not blind to the stimulus pair being exposed, thus reinforcing the need for a standardized mechanical means of presentation. Finally, although many of the Maine Scale questionnaires were completed by the patients' doctors after the patient had been tested, several were completed before the patient was tested. Thus the experimenter was not blind to the patient's diagnosis for all subjects.
To recapitulate, it will require a further study with larger groups to determine whether the trends found in the present study represent more than chance findings. If these trends are confirmed it will also be necessary to examine the M2 method of allocation in order to discover whether it has any practical use as a dimension of schizophrenia with clinical or experimental correlates.

Moreover, if future research determines that the present trends have validity then the results of the present study may be of more than theoretical interest. Hemsley (1977, 1978), has pointed out that environmental factors may play an important role in determining the form of schizophrenic symptomatology. "In those patients in whom the basic cognitive disturbance remains, any attempt to manipulate secondary abnormalities by such operant procedures might be expected to result either in a shift to a new method of adaptation or in an increase in 'error' responses manifest as an increase in florid symptomatology such as incoherence of speech". (Hemsley, 1977, p.172). In other words attempts at modifying the delusions of paranoid patients in whom the basic cognitive disturbance remains will likely be fruitless and may well lead to more florid symptoms.

In those paranoid patients in whom the primary cognitive disturbance has diminished there may still remain secondary abnormalities which no longer serve their formerly adaptive functions. The patient may still employ an approximation strategy as he processes information from his environment, or may continue to use a schemata-driven form of processing whereby he illusory correlates stimuli from the world around him in accordance with his delusional beliefs. Chapman's (1967) original study on illusory correlations found that the amount of illusory correlations declined with successive testings, though it was not clear what mechanism was at work such that subjects began to perceive reality more accurately. Presumably however, if it were logically or empirically demonstrated to a patient who no longer suffered the primary cognitive disturbance that events in his environment are not correlated in the way he perceives them to be, some improvement may be achieved. In personal construct terms this
may be seen as a controlled loosening of his formerly tight construct system.

Watts, Powell and Austin (1973) have demonstrated the effectiveness of such a treatment with three paranoid schizophrenics. The patients’ illness had ranged in duration from six to twelve years and by the time they were seen by the authors their general functioning was much improved. It appears that their remaining problems consisted primarily of paranoid beliefs. The authors developed with the patients a hierarchy of target beliefs. It was made clear to the subject that he "was only being asked to consider the facts and arguments discussed with him... The first move in discussing each belief statement was therefore to ask the subject what his evidence for it was". (Watts et al, 1973, p.360). Other interpretations and explanations of the patients' evidence were discussed and argued without the subject being pressed into acceptance of any of them. The subject himself was eventually encouraged to voice the arguments against his own beliefs. This treatment was successful in producing a significant reduction in the subjects' ratings of the strength of their paranoid beliefs.

One of the most interesting results of this study was the fact that disintegrated schizophrenics as defined by our M2 method of classification, showed a tendency to recall what they had seen more accurately than normals. There is currently much debate in the field of cognitive abnormalities in schizophrenia as to the significance of cognitive deficits (Chapman and Chapman, 1973). Schizophrenics are inferior to normals on most laboratory tasks while paranoids perform better than nonparanoids but not as well as normals (Shakow, 1971). By contrast, the present study predicted, on the basis of a model of schizophrenia, that a subgroup would show a different, indeed a superior performance to that of normals. Any abnormalities of this kind that are found are less open to alternative explanation (i.e. motivation, drug effects, institutionalization) than are deficits. It is likely that such an approach may be a fruitful path to follow in future research in this area.


Shakow, D., (1971). Some observations on the psychology (and some fewer on the biology) of schizophrenia. Journal of Nervous and Mental Disease, 153, 300-316.


**TABLE OF APPENDICES**

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APPENDIX 1

The Maine Scale

(from Vojtisek, 1976)

P1 Does the patient tend to suspect or believe on slight evidence or without good reason that people and external forces are trying to or do now influence his behaviour, control his thinking?
   1. No unjustified suspicions
   2. Will admit suspicion when pressed
   3. Easily admits suspicion
   4. Openly states others are trying to control him
   5. Has firm conviction that he is influenced or controlled.

P2 Does he tend to suspect or to believe on slight evidence or without good reason that some people are against him (persecuting, conspiring, cheating, depriving, punishing) in various ways?
   1. No unjustified suspicions expressed
   2. When pressed expresses belief that he is conspired against
   3. Frequently inclined to suspect
   4. Frank inclination to believe in persecution
   5. Strongly expresses conviction of persecution

P3 Does he have an exaggeratedly high opinion of himself or an unjustified belief or conviction of having unusual ability, knowledge, power, wealth, or status?
   1. No expressed high opinion of himself
   2. When pressed expresses a high opinion of himself
   3. Frequently expresses a high opinion of himself
   4. Open conviction of unusual power, wealth, etc.
   5. Strongly expresses conviction of grandiose or fantastic power, wealth, etc.

P4 Does he tend to suspect or believe on slight evidence or without good reason that some people talk about, refer to or watch him?
   1. No unjustified suspicions
   2. Will admit suspicion
   3. Easily admits suspicion
   4. Openly states that he is watched
   5. Has firm conviction of being watched
P5 Compared to others, how openly hostile is he? Does he show hostility or a high degree of ill will, resentment, bitterness, or hate?

1. No open hostility
2. Relatively little hostility
3. Some hostility
4. Rather hostile
5. Very hostile

N1 Does he have perceptions (auditory, visual) without normal external stimulus correspondence?

1. None
2. When pressed admits hallucinations
3. Easily admits hallucinations
4. Openly admits frequent hallucinations
5. Openly hallucinates

N2 On the basis of the integration of the verbal productions of the patient, does he exhibit thought processes that are confused, disconnected or disorganized?

1. As normal
2. Slight disorganization
3. Mild disorganization
4. Marked disorganization
5. Complete disorganization

N3 How incongruous are his emotional responses? (e.g. giggling or crying for no apparent reason or not showing any emotion when emotion would be appropriately shown)

1. As normal
2. Slightly different from normal
3. Responses somewhat incongruous
4. Distinctly incongruous
5. Very markedly incongruous

N4 How well orientated is he as to time? For instance does he know: (a) the season; (b) the month; (c) the calendar year; (d) the day of the week; (e) how long he has been in hospital?

1. As normal
2. Occasional confusion
3. Slight confusion
4. Frequent confusion
5. Marked continuous confusion
N5 Does he assume or maintain peculiar, unnatural, or bizarre postures?

1. None
2. On rare occasions
3. For short periods
4. Frequently
5. All the time
APPENDIX 2

Photograph of the experimental apparatus.
The first part of this questionnaire aims to discover the strength of association between different words. Look at each pair of words below and decide how strong the tendency is for the first word to call to mind the second word. For example, if there is a very strong tendency for the first word to call to mind the second, place a "1" in the space beside the pair. Likewise, if there is very little tendency for the first word to call to mind the second, place a "5" in the space, and so on.

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...tendency for the first word to call to mind the second.

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Bacon Tiger 4.82 Bacon Notebook 5.00 Bacon Eggs 1.18 Lion Tiger 1.36 Lion Notebooks 4.82 Lion Eggs 4.64 Boat Tiger 4.82 Boat Notebook 4.91 Boat Eggs 5.00 Blossom Tiger 4.36 Blossom Notebook 4.82 Blossom Eggs 4.82

This part of the questionnaire is looking at the strength of association between a sound and a picture. Look at the picture on the left and decide how strong the tendency is for the picture to call to mind each of the three sounds you will hear and which are described to the right of the picture.

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<td>Very little</td>
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...tendency for the picture to call to mind the sound.

Low pitch sound 3.01 High pitch sound 1.82 Intermittent sound 4.82

Low pitch sound 2.72 High pitch sound 4.64 Intermittent sound 4.82

Low pitch sound 1.64 High pitch sound 3.54 Intermittent sound 4.82

Finally, this time look at the picture on the left and decide how strong the tendency is for the picture to call to mind each of the words beside it.

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APPENDIX 4 (d)

A-Stimuli used in Task 4
APPENDIX 5

Example Cards.
APPENDIX 6

Instructions preceding each task

Introduction.

"The general idea of my research is to see how different people perform on various tasks I give them. Now I hope to give you four tasks which are all fairly similar to one another. You may feel a bit lost at times during the tasks but try to keep concentrating until the task is over".

Task 1.

"The first task involves looking at a number of cards on which you will see two words. Your task will be to try to roughly work out how often each word on the top occurs with each word on the bottom. You will see far too many cards to count so don't bother to try. Just do your best to form a general impression of what you see".

Task 2.

"The second task involves looking at a number of cards on which you will see a figure of a man and a word. Your task will be to try to roughly work out how often each figure occurs with each word. You will see far too many cards to count so don't bother to try. Just do your best to form a general impression of what you see".

Task 3.

"The third task again involves looking at a number of cards on which you will see two words. Your task will be to try to roughly work out how often each word on the top occurs with each word on the bottom. You will see far too many cards to count so don't bother to try. Just do your best to form a general impression of what you see".
Task 4.

"The fourth task involves looking at a number of figures which I will show you, at the same time as listening to different sounds. Your task will be to try to roughly work out how often each sound occurs with each figure. You will see far too many pairs of sounds and figures to count them, so don't bother to try. Just do your best to form a general impression of what you see and hear".
APPENDIX 7

Raw data for each subject.

Key to Raw data

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