

**FEAR OF RECURRENCE, SENSE OF COHERENCE AND
POSTTRAUMATIC STRESS SYMPTOMATOLOGY IN
CANCER SURVIVORS**

& RESEARCH PORTFOLIO

PART ONE

(Part Two Bound Separately)

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August 2002

**Submitted in Partial Fulfilment of the Requirements for the Degree of Doctorate in
Clinical Psychology**

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CHAPTER 1

SMALL SCALE SERVICE EVALUATION

Audit of a Triage System as Part of an Outpatient Clinical Psychology Department.

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Prepared in accordance with the guidelines for submission to *Clinical Psychology*

(Appendix 1.1)

Audit of a Triage System as Part of an Outpatient Clinical Psychology Department.

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ABSTRACT

An evaluation of a triage system set up in response to the NHS Executive requirement for audit, discussion of outcomes and limitations.

INTRODUCTION

In 1989 the NHS Executive made clinical audit a requirement for clinical professions including clinical psychology (DoH, 1989). Subsequent documents have expanded this to include a discussion of clinical governance and quality initiatives (DoH, 1997). Clinical audit has been recognised as one of the main elements of quality initiatives (Dickens, 1994). The DCP working group has responded by proposing that all psychologists should be involved in the audit process by evaluating and improving their practice (Cape, 1995).

However, despite encouragement from both the government (DoH, 1989) and the Division of Clinical Psychology, (Cape, 1995), there seems to be a reluctance on the part of psychologists to become involved in clinical audit. This could be a result of the fear of detecting the need for change either as a result of the intervention being ineffective or as a result of the therapist's inability to bring about change (Halstead, 1996). Furthermore, clinical audit is often perceived to be a time consuming endeavour (Halstead, 1996). As a result of this it is often neglected in favour of increasing patient caseloads and developing new initiatives for managing patient waiting lists. This is despite evidence indicating that time spent in audit of services may result in service development (Paxton, 1995) by impacting on waiting lists and efficiency. Paxton (1995) further suggests that clinical audit

may feasibly represent an active link between the two main roles inherent in the scientist practitioner model that is a fundamental part of the profession.

Consulting and Clinical Psychology Services (CCPS) is a multidisciplinary service that operates with a skill mix of clinical psychologists and other professions, including counselling psychologists, CBT nurse specialists and counsellors. This service was set up in response to the Mowbray report (Management Advisory Service, 1989) which highlighted the fact that psychological skills were no longer solely the domain of clinical psychologists. The report described a three level framework of psychological skill with level 1 as basic psychological activities, level 2 as circumscribed psychological activities and level 3 as specialist psychological intervention. The report notes that clinical psychologists are able to work at all three levels.

With an ongoing shortage of clinical psychologists it is important to recognise the role other professions have in the provision of psychological services. This skill mix allows range, effectiveness and cost-efficiency to be maximised without any loss to the quality of the service (SCPMDE, 1999). It allows the service to make the best use of the specialist expertise of clinical psychologists by allowing the majority of their time to be spent working with cases that require level 3 skills. However, establishing the complexity of a case to allow allocation to the appropriate discipline proved difficult based only on the referral letter. In response, a triage system was set up to provide an initial assessment carried out by a clinical psychologist, enabling appropriate allocation. The triage system also aimed to provide a system that would allow the prioritisation of need and possibly reduce waiting times by filtering out inappropriate referrals.

Referrals to CCPS are received and placed on a primary waiting list. The service aims to see all patients for an initial assessment within nine weeks of referral. An appointment for an initial assessment is sent out which includes an opt-in system. It had been recognised that 17% of outpatients fail to attend their first appointment (Madden and Hinks, 1987) which wastes the time of clinicians and as a result impacts on the waiting list. Opt-in systems are considered an effective method of reducing this problem (Startup, 1994). Patients are asked to fill-in and return a tear-off slip indicating if they are going to attend their appointment. They are given a return-by date. If the patient indicates they do not wish a further appointment or does not return their acceptance they are discharged at this point.

Assessment clinics are held by 11 psychologists in 12 locations, covering both north and south Ayrshire. Patients whose referral is inappropriate are discharged following their initial assessment and referred to an alternative service if this is required. Appropriate referrals are allocated to a secondary waiting list to await treatment and recommendation of the profession that works at the most appropriate level for their difficulties is made.

The new triage system also presented the CCPS with an opportunity to look at audit of the service. A database was set up using information recorded at the initial assessment appointment.

One year on, there is now a suitable quantity of data to allow an audit of the service to be carried out. The aims of this audit were to:

- improve our understanding of the characteristics of the client population
- provide information regarding type and source of referral
- provide data to guide future developments in service provision
- provide information regarding the suitability of the system as an audit tool

The information for the database used in this study is only collected at the initial triage assessment. The scope of the study is therefore limited to information available at that time.

METHOD

There were 714 participants included in this audit. This was all the patients who were referred to and assessed as part of the triage system between the period of 1 May 1999 and 30 April 2000. Those who opted-out or Did Not Attend (DNA) on first appointment were not included in the sample as none of this data were collected.

Data were collected throughout the year by the assessing psychologists and were entered into the computer by an assistant psychologist. The data for the period 1 May 1999 - 30 September 1999 were collated on Access and the period of 1 October 1999 - 30 April 2000 were collated on SPSS. In order to carry out data analysis the data on Access were transferred to the SPSS database.

The information was gathered, by the assessing psychologist, using a proforma (Appendix 1.2) and included the following information:

- DOB
- gender
- referral date
- referring agency
- assessment date
- presenting problem/s
- contributing factor/s
- problem category
- allocation to secondary waiting list
- priority on waiting list
- refer out-with CCPS
- type of intervention required
- individual or group intervention

The data from these variables were analysed using descriptive statistics. Individual anxiety and mood disorders were specified on the database. However, for purposes of analysis these disorders were combined into two categories, anxiety disorders and mood disorders as classified by DSM-IV (APA, 1994).

RESULTS

Descriptive data

Demographics

Of the 714 participants, 421 (59%) were female, 292 (40.9%) were male and there was one data point missing. The age distribution of those attending was as follows:

Table 1: Gender distribution according to age

	Male Frequency	Male Percentage	Female Frequency	Female Percentage	Overall Percentage
16 - 20	23	3.2	29	4.1	7.3
21 - 30	71	9.9	105	14.8	24.7
31 - 40	90	12.7	113	15.8	28.5
41 - 50	51	7.1	84	11.8	18.9
51 +	52	7.3	79	11.1	18.4

The table shows the percentages of male and female referrals falling into each age band.

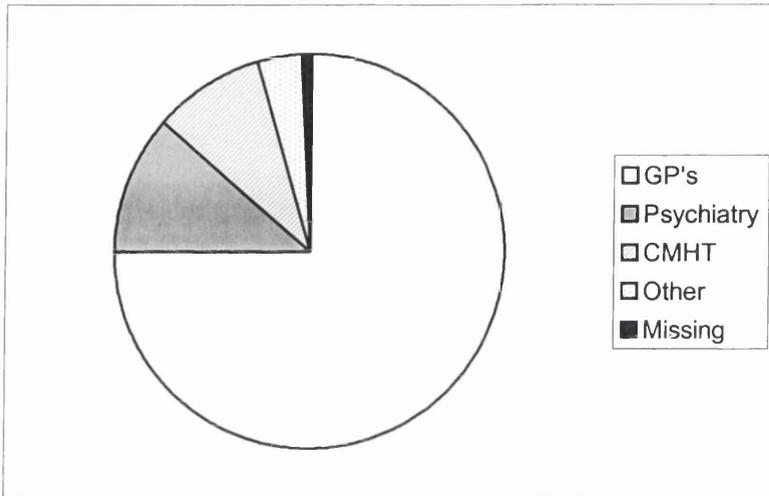
There were 16 (2.2%) data points missing from this group.

Time to first appointment

The average waiting time from referral to triage assessment appointment was 10.39 weeks (SD 7.21).

Source of referral

Figure 1: Source of referral



The figure shows percentage of referrals from each source.

Five hundred and thirty five (74.9%) referral's were received from GP's, 81 (11.3%) referral's from psychiatry, 66 (9.2%) from CMHT's, and 26 (3.7%) from other sources. There were 5 cases missing from the database. CMHT referrals are received from both psychiatry and CPN's.

Presenting problem

Table 2: Primary and Secondary Presenting Problem

	Primary Frequency	Primary Percentage	Secondary Frequency	Secondary Percentage
Anger	49	6.9	26	3.6
Anorexia	3	0.4	0	0
Anti-Social	2	0.3	2	0.3
Anxiety disorder	239	33.5	127	17.8
Attention deficit	1	0.1	0	0
Bulimia	0	0	1	0.1
Carer management	2	0.3	0	0
Communication	1	0.1	2	0.3
Encopresis	1	0.1	1	0.1
Family problems	4	0.6	6	0.8
Gambling	1	0.1	0	0
Grief reaction	11	1.5	7	1.0
Hypersomnia	2	0.3	0	0
Illness behaviour	11	1.5	3	0.4
Immature	2	0.3	0	0
Insomnia	5	0.7	2	0.3
Intellectual/memory impairment	21	2.9	1	0.1
Interpersonal skills	1	0.1	2	0.3
Irritability	0	0	3	0.4
Marital problems	14	2.0	14	2.0
Mood disorder	172	24.1	78	10.9
Motivation	0	0	1	0.1
Not otherwise specified	42	5.9	16	2.2
Obsessional	8	1.1	5	0.7
Over-eating	3	0.4	1	0.1
Pain	6	0.8	3	0.4
Parental management	1	0.1	1	0.1
Peer relationships	6	0.8	2	0.3
Perceptual deficits	1	0.1	0	0
Psychosexual dysfunction	7	1.0	2	0.3
Ruminations	2	0.3	3	0.4
Schizoid	1	0.1	1	0.1
Self injury	1	0.1	1	0.1
Separation anxiety	2	0.3	1	0.1
Sexual identity	0	0	2	0.3
Social relationship	7	1.0	9	1.3
Social withdrawal	0	0	3	0.4
Stereotypy	0	0	1	0.1
Stress adjustment	37	5.2	37	5.2
Substance use - alcohol	10	1.4	7	1.0
Substance use - drugs	2	0.3	5	0.7
Temper tantrums	4	0.6	2	0.3
Work stress	13	1.8	10	1.4
Missing data	19	2.6	319	44.6

The table show the number of primary and secondary presenting problems by problem category.

Anxiety and mood disorders accounted for the largest number of referrals. Two hundred and thirty-nine (33.5%) of the referrals had an anxiety disorder as the primary presenting problem and a further 127 (17.8%) referrals had an anxiety disorder identified as the

secondary presenting problem. Mood disorders accounted for 172 (24.1%) of the primary presenting problems, with a further 78 (10.9%) as a secondary problem. Other disorders that presented in fairly large numbers included anger management (49, 6.9%) and stress adjustment (37, 5.2%).

Allocation to secondary waiting list

Table 3: Discharges following initial assessment

	Frequency	Percentage
Difficulty resolved prior to appointment	14	19.2
Single session sufficient	30	41.1
Other	29	39.7
Total	73	100

The table shows the number of referrals discharged following initial assessment and the reason for this discharge.

Seventy three (10.2%) of the participants were not offered further appointments within the CCPS. Fourteen of these indicated that their difficulties had been resolved prior to their appointment date. Thirty felt that a single session had been sufficient to alleviate their problems and a further 29 were discharged for a variety of other reasons. However, due to the limitations of the database these are not accessible.

Table 4: Priority allocation on secondary waiting list

	Frequency	Percentage
High priority	177	24.8
Medium priority	414	58.0
Low priority	123	17.2

The table shows the number of referrals allocated to each priority category on the waiting list.

Of those who were offered a place on the secondary waiting list 177 (27.6 %) were given high priority and 414 (64.6%) were given medium priority on the list. One hundred and twenty-three (17.2%) were not given a priority position on the waiting list. These are placed in the low priority category on the list.

Table 5: Context of intervention

	Frequency	Percentage
Individual treatment	556	77.9
Group intervention	11	1.5
Couple therapy	2	0.3
Missing data	145	20.3

The table shows the number of referrals allocated to each intervention type.

The majority, of the participants (556 (77.9%)) were offered individual follow-up treatment sessions. Eleven (1.5%) were offered group intervention and 2 (0.3%) were offered couple therapy. However, 145 (20.3%) of the data were missing for this category.

Table 6: Intervention required

	Frequency	Percentage
CBT nurse specialist	193	27.0
Clinical psychologist	182	25.5
Counsellor	115	16.1
Counselling psychologist	74	10.4
Clin. Psy. Or CBT	12	1.6
Clin. Psy. Or Couns. Psy.	5	0.7
Missing data	133	18.7

The table shows the number of referrals that were allocated to each discipline within the service.

Following assessment referrals were also allocated to the most appropriate discipline. One hundred and ninety-three (27.0%) were allocated to be seen by a CBT nurse specialist. One hundred and eighty-two (25.5%) were allocated to a clinical psychologist, 115 (16.1%) to a counsellor and 74 (10.4%) to a counselling psychologist. A further 12 (1.6%) were

allocated to either a clinical psychologist or a CBT specialist, and 5 (0.7 %) were allocated to either a clinical psychologist or a counselling psychologist. Missing data accounted for the remaining 133 (18.7 %) participants.

Forty one (5.7%) of those taken on by the service were referred to other services out-with the CCPS including psychiatry, practice based counsellor, addiction services, voluntary organisations, CMHT, rehab/neuro and learning disability services to be offered concurrent assessment and treatment.

DISCUSSION

Implications for the service

The majority of referrals are received from GP's. This is to be expected in a primary care service. Other sources of referrals include hospital psychiatry and psychiatry and CPN's based at CMHT's.

As described in the method section, the presenting problems that come under the anxiety disorder classification in DSM-IV were combined, as were those which were mood disorders. As a result of this, these two categories represent the majority of patients referred (Table 2). This finding is to be expected given the current prevalence rates of these disorders in the primary care setting (Nisenson et al., 1998; Coyne et al., 1994; Espie and White, 1986b). Other presenting problems for which there are frequent referrals include anger management and stress adjustment.

CCPS aims to see all referrals for initial assessment within nine weeks of referral. The average waiting time of 10.39 weeks indicates that this target is almost being met. However, to establish the real effect of the triage system on waiting time it would be necessary to examine the time between triage appointment and first treatment session. Unfortunately, this is beyond the scope of this study.

Seventy three participants were discharged from the CCPS following their initial assessment (Table 3). Fourteen of these reported that their problem had been resolved prior to their attendance at CCPS. Thus some sources of resolution may occur while the person is awaiting clinical contact. Although CCPS is almost meeting their target waiting time, some patients are still waiting considerably longer and their difficulties may be resolved during this period. Thirty patients felt one session was sufficient. In these cases, it is possible that acknowledgement/normalisation of their problems or self-help information was sufficient for them to resolve their difficulties.

CCPS has introduced a prioritisation scheme that allocates patients to high priority, medium priority or low priority depending on the severity of the disorder. Although there are currently no target maximum waiting times by priority, medium priority cases are automatically moved to high priority after eight weeks on the secondary waiting list. Those in the low priority list remain there until they are seen. Therefore, it is possible that they will wait a considerable time for a treatment appointment.

Seventy eight percent of those referred were offered individual treatment compared to only 0.3% who were offered a group intervention (Table 5). However, 20% of the data were

missing from this variable making these data difficult to interpret. It is possible that for some of those offered individual treatment, a group would be suitable, however, this is currently unavailable. Groups have been shown to be effective for a number of disorders, for example anxiety disorders (White et al., 1992).

Clinical psychologists and CBT nurse specialists are allocated the most referrals following the initial assessment, with CBT nurse specialists receiving slightly more than clinical psychologists. This has considerable implications for clinical psychology. As previously discussed clinical psychologists are able to work at all three skill levels (Management Advisory service, 1989) and so are able to treat patients who require different levels of skill. The allocations made to each discipline following initial assessment are recommendations and as such do not exclude clinical psychologists from taking patients from another disciplines waiting list if time is available. Therefore, the allocations do not imply the caseload of each discipline. However, allocation to any particular discipline does give an indication of the perception of the skill level required for the patients referred to CCPS. These results imply that most patients fall into the skill level 2 category and as a result this does have implications for employment of staff and cost-efficiency.

Patients' non-attendance of appointments results in clinicians time being wasted (McPherson et al., 1996; Madden and Hinks, 1987). In the current climate where there is continual pressure to reduce waiting lists wasted sessions are an important consideration. High DNA rates can also lower the morale of clinicians (Startup, 1994). The new triage system has included an opt-in system in an attempt to reduce the first appointment DNA rate. However, this has not been included in the database and so it is not possible to

measure the success of this initiative. There is also no information on the DNA rate once treatment has started. An estimate of wasted time would allow an estimate of the cost effectiveness of the department (McPherson et al., 1996).

Limitations of the study

Clinical audit is a requirement not only by request of the Division of Clinical Psychology (Cape, 1995), but also of the NHS Executive (DoH, 1989). Therefore, it should be given time and consideration. Guidelines for the development of audit systems have been proposed by a number of people. Crombie et al., (1993) and the SCPME (Marinker, 1990) propose a similar audit cycle which includes selecting a topic, setting standards, measuring practice against standards, implementing change and review.

CCPS has begun this process by selecting a topic and setting standards. However, the database does not adequately answer whether practice, in this particular service, meets all the standards set and it could be extended to examine other areas. CCPS has set standards regarding length of time from referral to triage assessment appointment. However, this does not indicate if patients are waiting less time until treatment than prior to the triage system. Consideration to the time between triage appointment and first treatment appointment is required.

One of the aims of the triage system was to reduce the first appointment DNA rate using an opt-in system. It was hope that this would impact on the waiting list. However, the success of this initiative is unclear as this information is not collected on the database. This information could be useful in establishing whether practice meets the standards set.

The audit was also limited by large quantities of data that were missing from the database. For example, 20% of the data allocating those referred to individual or group interventions was missing. This limits the usefulness of conclusions that can be drawn from some areas of the study.

CONCLUSIONS

CCPS has begun to answer the NHS executive requirement to carry out clinical audit. However, as highlighted above, further consideration needs to be given to the DNA rate and waiting times from referral to treatment appointment. Without consideration of these areas it is difficult to evaluate the effect of the triage and opt-in systems in terms of their original aims of reducing waiting times and reducing DNA rates.

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CHAPTER 2

MAJOR RESEARCH PROJECT LITERATURE REVIEW

Fear of Recurrence, Sense of Coherence and Posttraumatic Stress Disorder in Cancer Survivors: A Systematic Review of the Literature

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Prepared in accordance with the guidelines for submission to

Psycho-Oncology (Appendix 2.1)

**Fear of Recurrence, Sense of Coherence and Posttraumatic Stress Disorder in Cancer
Survivors: A Systematic Review of the Literature**

Short Title: Fear of Recurrence, Sense of Coherence and PTSD in Cancer Survivors: A
Review.

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SUMMARY

Life-threatening illnesses, such as cancer, may precipitate Posttraumatic Stress Disorder (PTSD). However illnesses are different from other traumas in both immediacy and degree of life threat, and therefore direct comparability with general theoretical models of PTSD cannot be assumed. This paper considers a cognitive model of PTSD in relation to cancer patients. The author proposes possible links with the concepts fear of recurrence and sense of coherence in moderating and mediating the development and maintenance of PTSD. A systematic review of the literature in this field is then conducted. Overall the quality of the literature in this field was poor. However, it did suggest that PTSD in cancer survivors does fit within the theoretical model of PTSD outlined. Little research has been carried out examining the possible role of fear of recurrence or sense of coherence in this process. The authors suggest this as an area for future research as it has implications for early intervention in those diagnosed with cancer that are at increased risk of developing persistent PTSD.

INTRODUCTION

Given that up to 43.4% of people with cancer experience psychological distress (Zabora *et al.*, 2001) gaining an understanding of psychosocial adjustment to cancer should be a central concern of clinicians in the field (Brennan, 2001). Depression and anxiety are just some of the types of psychological distress that can be experienced (Zabora *et al.*, 2001). Since the publication of the Diagnostic and Statistical manual of the American Psychiatric Association – Fourth Edition (APA, 1994) cancer has been recognised as a traumatic event capable of precipitating PTSD. Studies to date report estimated rates of PTSD from 1.9% (Green *et al.*, 1998) to 12% (Tjemsland *et al.*, 1998) in cancer populations. However, cancer differs from other traumas in both immediacy and degree of life threat. It cannot, therefore, be assumed that PTSD related to cancer fits within current models of PTSD or that its symptom structure will be the same.

This review examines a recent model of PTSD and its theoretical links with both a belief of the world as comprehensible, manageable and meaningful (sense of coherence) and fear of cancer recurrence. The literature relating to cancer survivors fear of recurrence, sense of coherence and PTSD is also systematically reviewed.

A Cognitive Model of Posttraumatic Stress Disorder

Posttraumatic Stress Disorder is commonly diagnosed following traumatic events such as assault, disaster and life threatening illness. Posttraumatic stress (PTS) symptoms include re-experiencing thoughts, images or feelings associated with the event, avoidance of stimuli associated with the event and increased arousal as indicated by difficulties with

concentration, irritability or sleep disturbance. Many people experience some of these symptoms immediately following a traumatic event (Ehlers and Clark, 2000), although most are able to recover in the subsequent few weeks and months. However, for some the symptoms persist beyond three months, becoming a chronic or persistent condition.

Ehlers and Clark (2000) outlined a model of persistent PTSD, which proposes that PTSD persists in those who process their trauma in a way that leads to “a sense of serious, current threat” (p.320). Ehlers and Clark’s (2000) model is considered particularly relevant to cancer populations due to its emphasis on cognitive theories of anxiety which suggest that anxiety occurs as a result of perceived impending threat. Given that cancer recurrence is a possibility in most cancers it is possible that those who experience cancer are likely to have concerns about future threat of cancer. Ehlers and Clark’s model (Ehlers and Clark, 2000) proposed that two key processes lead to a sense of serious, current threat. These are:

- Individual differences in the appraisal of the trauma and/or its sequelae.
- Individual differences in the nature of the memory for the event and the memory’s links to other autobiographical memories.

It is proposed that individuals with persistent PTSD are unable to see the trauma as a time-limited event and therefore, may exaggerate the possibility of further catastrophic events happening to them. The model also suggests that people with persistent PTSD find it difficult to recollect an accurate memory of the traumatic event and report a high frequency of involuntary intrusive memories (see Fig. 1). These involuntary memories can involve re-experiencing aspects of the event in a very vivid and emotional way. The individuals’

appraisals of the event will influence their memories, thus those who appraise their trauma negatively are more likely to remember events that confirm their appraisal. The model outlines that the situation is further exacerbated by attempts to control symptoms such as intrusive memories, using maladaptive strategies. These strategies can result in an increase in the posttraumatic stress symptoms experienced. For example, attempts to push all thoughts relating to the trauma out of mind, can result in an increase in the number of unwanted intrusive thoughts being experienced. The coping strategies used to control PTS symptoms and current threat, are likely to be influenced by prior experience and beliefs.

Although some aspects of this model still have to undergo empirical evaluation, support has been provided for a number of the central features. Dunmore, Clark and Ehlers (1999) found that negative appraisals of the trauma (e.g. I blame myself because my actions made things worse; I feel like other people are ashamed of me now) predict PTSD persistence. Foa *et al.* (1995) found that the extent to which an individual is able to alter their narrative of the event to become more organised and coherent predicts treatment outcome. Several of the strategies such as safety behaviours and rumination, have been shown to predict persistence of PTS Symptomatology (Dunmore *et al.*, 1999), as have memory fragments (Murray *et al.*, 2002). Although further evidence is required the model is consistent with the main clinical features of PTSD, providing a framework for understanding and treating PTSD.

Insert Figure 1 about here

The Sense of Coherence Construct

Following a traumatic experience many people are able to adjust well and continue with their lives (Ehlers and Clark, 2000), often with a more positive outlook (Park and Folkman, 1997). Several authors (Antonovsky, 1979; Kobasa *et al.*, 1982; Rosenbaum, 1990) have outlined models of stress resistance that aim to explain this. One such model is the sense of coherence construct proposed and developed by the late Aaron Antonovsky over the last twenty years (Antonovsky, 1979; 1987; 1991). His model highlights the inadequacies of viewing disease in a manner that tries to explain why people get sick (pathogenic orientation). At best, he feels, this orientation highlights the role of coping mechanisms as buffers or moderators of stressors (Antonovsky, 1993). Antonovsky proposes that given the level of stressors human's experience, the mystery is that they maintain some level of health and survive at all.

Antonovsky outlined a model that focused on the origins of health (salutogenic orientation) rather than the origins of disease. This model proposes that the secret of health is "adaptive coping that is moderated by generalised resistance resources". These resources include wealth, social support, ego strength, coping strategies, and cultural stability. They are seen as leading to life experiences that promote the development of a strong sense of coherence.

He defined sense of coherence as follows:

"a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from ones internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges worthy of investment and engagement" (Antonovsky 1987; p. 19).

In other words, those with a high sense of coherence have a way of seeing the world that facilitates successful coping with the many complex stressors that are confronted in the course of living (Antonovsky, 1993). He called the three components described above, comprehensibility, manageability and meaningfulness and has constructed the Sense of Coherence Scale (SOC Scale) based on these three components. A strong sense of coherence is implicated in maintaining and increasing an individual's health status, therefore, those with a strong sense of coherence are less likely to experience stress.

It is hypothesised that sense of coherence is a mediating and moderating factor for PTSD. Ehlers and Clark's (2000) model highlights the role of individual's prior experiences, beliefs and coping strategies in the development and maintenance of PTSD and, as described, Antonovsky encompasses these factors in his sense of coherence construct. It is proposed that sense of coherence can be implicated in box 1 (Fig. 1) of Ehlers and Clark's (2000) model.

Fear of Recurrence

Fear of disease progression or recurrence is one of the main causes of anxiety and psychological distress in individuals who have chronic illness (Herschbach *et al.*, 1997). Following diagnosis and treatment for cancer, people often become concerned that it will come back. This concept has been termed 'fear of recurrence' and is implicated when considering Posttraumatic Stress Disorder in those who have experienced a life threatening illness, particularly cancer. Cancer survivors have to live with the fear that their disease could recur and possibly become unmanageable (Sanders and Kardinal, 1977). O'Neill suggests that most cancer survivors experience fear of recurrence at some level (1975).

However, others have found that 50% of patients expressed complete surprise on learning that they had a recurrence (Chekryn, 1984). People have different responses to the thought of recurrence and it is possible that these responses are mediated by sense of coherence. Fear of recurrence is, however, also implicated in the cognitive model of PTSD proposed by Ehlers and Clark (2000) and may help explain why Posttraumatic Stress Disorder has been found in cancer survivors. Ehlers and Clark's model is based on the premise that persistent PTSD results in those who process their trauma in a way that leads to a sense of serious, current threat. When experienced on an intense level, fear of recurrence could be described as a sense of serious, current threat. This will make those with fear of recurrence more prone to experience PTS symptoms and to develop PTSD. Fear of recurrence can therefore be implicated in box 2 (Fig. 1) of the cognitive model of PTSD (Ehlers and Clark, 2000).

Having outlined the hypothesised relationship between Posttraumatic Stress Disorder, sense of coherence and fear of recurrence in cancer survivors, the literature relating to each of these concepts with regard to cancer survivors will now be reviewed.

CRITERIA FOR INCLUDING STUDIES FOR THIS REVIEW

Study Designs

Randomised trials, cohort studies, case control studies and cross-sectional studies.

Types of Participant

Persons aged 18 or over, who had a primary diagnosis of adult cancer and whose disease was in remission.

Types of Studies

Criteria for selection included literature that examined a population with a primary diagnosis of adult cancer that was in remission, which addressed any or all of the following issues:

1. The incidence and prevalence of Posttraumatic Stress Disorder in cancer patients.
2. The incidence and prevalence of Fear of Recurrence in cancer patients.
3. The role of Sense of Coherence in the adjustment of cancer patients.

TYPES OF OUTCOME MEASURE

1. **Rates of PTSD:** Impact of Events Scale (IES) (Horowitz *et al.*, 1979), PTSD Checklist-Civilian Version (PCL-C) (Weathers *et al.*, 1991), Structured Clinical Interview for DSM-IV-non-patient version-PTSD (SCID-NPV-PTSD) (Spitzer *et al.*, 1990), Structured Clinical Interview for DSM-IV (SCID for DSM-IV) (First *et al.*, 1995), Trauma Experience Questionnaire (Widows *et al.*, 2000), Trauma History Questionnaire (Green, 1996); THQ), Stressful Illness Experience (SIE) scale (Green *et al.*, 1998).
2. **General Psychological Morbidity:** Symptom Checklist-Revised (SCL-90-R) (Derogatis, 1977), Medical Outcomes Study-20 Items (MOS-20; (Stewart *et al.*, 1988),

Brief Symptom Inventory (BSI) (Derogatis, 1985), Brief COPE (Carver, 1997), Symptom Distress Scale (Holmes, 1989), Social Constraint Questionnaire (Jacobsen *et al.*, 1998), DUKE-Social Support Questionnaire (DUKE-SSQ; (Broadhead *et al.*, 1988), Coping Response Inventory (CRI) (Moos, 1993), Interpersonal Support Evaluation List – Short Form (ISEL-SF) (Peirce *et al.*, 1996).

3. **Level of Fear of Recurrence:** Fear of Recurrence Questionnaire (Northouse, 1981), Mishel Uncertainty in Illness Scale (Mishel, 1981), Growth Through Uncertainty Scale (Mishel and Fleury, 1994).
4. **Level of Sense of Coherence:** Sense of Coherence Scale (Antonovsky, 1987).
5. **Anxiety:** Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983), Profile of Mood State – Short Form (McNair *et al.*, 1971).
6. **Depression:** HADS (Zigmond and Snaith, 1983), Profile of Mood State – Short Form (McNair *et al.*, 1971), Profile of Mood State (POMS) (McNair *et al.*, 1992), Center for Epidemiological Studies Depression (CES-D) (Radloff, 1977).

SEARCH STRATEGIES FOR IDENTIFICATION OF STUDIES

Databases

MEDLINE, PsycINFO, EMBASE, CINAHL, Cochrane

Electronic Search Strategy

1. All references to posttraumatic stress disorder, stress response syndromes, adjustment disorder, fear of recurrence, illness uncertainty, and sense of coherence in all databases.
2. Reference lists of studies included in the review were searched.

Contact

1. Contact with key individuals (Northouse, Herschbach, Weathers, Keane, Kornblith).

Hand Search

Psycho-oncology (1996 (5,1) – 2002 (11,1))

Journal of Psychosocial Oncology (1983 (1,1) - 2001 (19,4))

METHODS OF REVIEW

Selection of Studies

All potential studies were reviewed by the author to determine if they fulfilled the inclusion criteria.

Data Abstraction

Data were abstracted from each article relating to study design and quality, patient demographics and cancer status, and measurement instruments and outcomes.

Quality Assessment

Studies were graded according to their design as follows (adapted from MacMahon and Lip, 2002):

- Ia Prospective, longitudinal studies with sufficient patient numbers, well-matched groups and well-validated measurement instruments.
- Ib Prospective, longitudinal studies with low patient numbers, but with well-matched groups and well-validated measurement instruments.
- IIa Cross-sectional studies with sufficient patient numbers, well-matched groups and well-validated measurement instruments.
- IIb Cross-sectional studies with low patient numbers, but with well-matched groups and well-validated measurement instruments.
- IIIa Prospective, longitudinal studies with sufficient patient numbers, but poorly-matched groups and/or less well-validated instruments.
- IIIb Prospective, longitudinal studies with low patient numbers, poorly-matched groups and/or less well-validated instruments.
- IVa Cross-sectional studies with sufficient patient numbers, but poorly-matched groups and/or less well-validated instruments.
- IVb Cross-sectional studies with low patient numbers, poorly-matched groups and/or less well-validated instruments.

Va Prospective, longitudinal studies with sufficient patient numbers, but no groups and/or less well-validated instruments.

Vb Prospective, longitudinal studies with low patient numbers, no groups and/or less well-validated instruments.

VIa Cross-sectional studies with sufficient patient numbers, but no groups and/or less well-validated instruments.

VIb Cross-sectional studies with low patient numbers, no groups and/or less well-validated instruments.

DESCRIPTION OF POSTTRAUMATIC STRESS DISORDER STUDIES

Excluded Studies

Twenty-seven studies related to PTSD in adult cancer survivors were identified. Overall, 16 of these studies did not meet the criteria for inclusion in this review. Fourteen studies were excluded as they included patients who were not disease free (Brewin *et al.*, 1998; Cella *et al.*, 1990; Epping-Jordan *et al.*, 1994; Ey *et al.*, 1998; Hampton and Frombach, 2000; Kelly *et al.*, 1995; Khalid and Gul, 2000; Lepore and Helgeson, 1998; Manne, 1999; Naidich and Motta, 2000; Primo *et al.*, 2000; Tjemsland *et al.*, 1996a; b; 1998). One study was excluded as it included both adults and adolescents in its sample (Lesko, 1990) and one paper was excluded as it was narrative (Neel, 2000).

Included Studies

Twelve studies met the inclusion criteria (Alter *et al.*, 1996; Andrykowski and Cordova, 1998; Andrykowski *et al.*, 2000; Andrykowski *et al.*, 1998; Baider and De-Nour, 1997; Cordova *et al.*, 1995; Cordova *et al.*, 2000; Green *et al.*, 1998; Jacobsen *et al.*, 2002; Jacobsen *et al.*, 1998; Mundy *et al.*, 2000; Widows *et al.*, 2000).

Design

Ten studies were cross-sectional in nature (Alter *et al.*, 1996; Andrykowski and Cordova, 1998; Andrykowski *et al.*, 1998; Baider and De-Nour, 1997; Cordova *et al.*, 1995; Cordova *et al.*, 2000; Green *et al.*, 1998; Jacobsen *et al.*, 1998; Mundy *et al.*, 2000; Widows *et al.*, 2000). Two studies were prospective longitudinal in nature (Andrykowski *et al.*, 2000; Jacobsen *et al.*, 2002).

Setting

Eleven studies were conducted in the USA (Alter *et al.*, 1996; Andrykowski and Cordova, 1998; Andrykowski *et al.*, 2000; Andrykowski *et al.*, 1998; Cordova *et al.*, 1995; Cordova *et al.*, 2000; Green *et al.*, 1998; Jacobsen *et al.*, 2002; Jacobsen *et al.*, 1998; Mundy *et al.*, 2000; Widows *et al.*, 2000), and one in Israel (Baider and De-Nour, 1997).

 Insert Table 1 about here

REVIEW OF STUDIES OF PTSD IN CANCER SURVIVORS

An early study by Cordova *et al.* (1995) examined the quality of life and cancer-related PTSD-like symptoms in 55 breast cancer survivors. Using the symptom method of diagnosis, where scores of 3 or more on the PCL-C are considered a symptom and the DSM-IV diagnostic rule is then followed (Weathers *et al.*, 1993), 5% of the sample met DSM-IV criteria for current PTSD. These findings suggest that the prevalence of PTSD in breast cancer survivors may exceed base rates of these symptoms in the general population (0.5% in males, 1.3% in females) (Helzer *et al.*, 1987). Increased PTSD symptoms were found to be associated negatively with quality of life, income and age.

Alter *et al.* (1996) also examined cancer-related PTSD in cancer survivors. Twenty-seven patients, who were at least 3 years from diagnosis and were involved in no active treatment, were interviewed using an adapted version of the Structured Clinical Interview for DSM-III-R (Spitzer *et al.*, 1990). They were compared against a community-based control group. Four percent of the survivor group met criteria for current PTSD and 22% of the survivor group met criteria for lifetime PTSD. None of the control group met criteria for either type of PTSD. This supports Cordova *et al.*'s (1995) findings that PTSD is more common in the cancer population than in the general population. It was noted that the symptoms described by adult cancer survivors were similar to those of individuals who have experienced other types of traumatic events. This study was conducted as part of the field trials for inclusion of life-threatening illness as a trauma capable of precipitating PTSD in DSM-IV (APA, 1994).

A study by Baider and De-Nour (1997) questioned the findings that cancer patients suffer from PTSD as defined by DSM-IV. Two hundred and eighty-three female patients with diagnosed early-stage breast cancer were administered the IES (Horowitz *et al.*, 1979). None of these patients were diagnosed as having PTSD although some had high scores on the IES. A strong relationship was found between intrusions as measured by the IES (Horowitz *et al.*, 1979) and psychological distress as measured by the BSI (Derogatis, 1985) but only a minimal relationship ($R^2 = 0.07$) was found between avoidance and psychological distress. Many of the patients showed no symptoms of increased arousal as measured by the BSI. Thus Baider and De-Nour (1997) concluded that although cancer patients did use cognitive styles that are typical of PTSD, their symptoms were not fully typical. This is contrary to the findings of both Cordova *et al.* (1995) and Alter *et al.* (1996) who suggest that PTSD is a relevant diagnosis in cancer populations.

Andrykowski and Cordova (1998) examined PTSD symptoms in 82 breast cancer survivors who were between 6 and 72 months from treatment completion. The PCL-C (Weathers *et al.*, 1991) was used to assess PTSD symptomatology. Approximately 5% of the sample met criteria for formal diagnosis of current cancer-related PTSD and an additional 5-15% reported sub-dromal levels of PTSD symptoms. Specific risk factors that were identified for higher PTSD symptoms by this study include less time since treatment completion, greater traumatic history prior to cancer (for example rape, severe motor vehicle accident, or violent crime), less social support and more advanced disease.

Andrykowski *et al.* (1998) conducted a study to determine the prevalence of PTSD in 82 breast cancer survivors and to determine the sensitivity of the PCL-C as a screening

instrument for PTSD in this population. The SCID-NP-PTSD (Spitzer *et al.*, 1990) was used to determine the PCL-C's validity in this population. Prevalence rates of 6% for current and 4% for lifetime PTSD were found using the SCID-NP-PTSD. The PCL-C was not fully accurate for the identification of PTSD as some false negatives did occur. However, it is important to consider that this study was conducted using telephone interview which may have affected the outcomes reported. They concluded that cancer diagnosis and treatment can precipitate PTSD and that the PCL-C is a cost-effective screening tool for detection of PTSD in this population.

Green *et al.* (1998) examined the prevalence of PTSD in 160 breast cancer survivors. All participants were between 4 and 12 months post-treatment. Participants were assessed using the SCID for DSM-III-R, the IES, the Trauma History Questionnaire (THQ) and the Stressful Illness Experience (SIE) scale. Acute stress disorder and PTSD were assessed separately and independently for cancer and non-cancer stressors. Three percent of this sample met stringent diagnostic criteria for cancer-related PTSD, although there was a much higher prevalence of PTS symptomatology reported (36%). These results are consistent with the findings of Alter *et al.* (1996) (4%) and Cordova *et al.* (1995) (5-10%). The authors suggest that the slightly higher rates of Cordova *et al.* (1995) may be attributable to the use of a self-report measure to assess PTSD which can over-estimate those who meet diagnostic criteria.

Jacobsen *et al.* (1998) used the PCL-C to assess the prevalence and correlates of PTSD symptoms in 43 women who had undergone autologous bone marrow transplantation (ABMT) for breast cancer. Nineteen percent of this sample met DSM-IV criteria for the

current diagnosis of PTSD. Those with longer hospital stays, more advanced disease when their transplant occurred and who were less well educated, reported more PTSD symptoms. These prevalence rates are higher than those previously reported by other authors. Jacobsen *et al.* suggest that this may be due to the women in this study having under-gone ABMT which has a higher mortality rate than standard treatments and has side effects that may be perceived as more aversive than other treatments. The women in this study also had more advanced disease and were a younger cohort than previous studies. Both these factors have previously been shown to be associated with increased PTSD symptomatology (Andrykowski and Cordova, 1998; Cordova *et al.*, 1995).

A subsequent study by the same group (Widows *et al.*, 2000) examined 23 male and 79 female bone marrow transplant survivors. The PCL-C and the Structured Clinical Interview for DSM-IV disorders Non-Patient Version (SCID-I/NP) (First *et al.*, 1995) were used to assess PTSD symptomatology. Five percent of this group met DSM-IV criteria for current PTSD. Greater PTSD symptoms were associated with more negative appraisals of the treatment experience, greater use of avoidance-based coping strategies, lower levels of social support and greater inhibition in discussing experiences. The discrepancy in the prevalence rates reported by the two studies was explained by improvements in supportive care and more effective drugs for the control of side effects.

Andrykowski *et al.* (2000) examined the stability of posttraumatic stress symptoms in 46 breast cancer survivors. All participants had completed treatment and had been in remission for between 3-60 months. An initial telephone interview was conducted using the PCL-C and the Duke-SSQ. This was followed up one year later with a similar

telephone interview. Results suggest no general diminishing of PTS symptomatology over time when the whole group is considered. However, examination of the individual scores showed fluctuations did occur with both increases and decreases in PCL-C scores being observed. The authors propose that this could indicate delayed onset PTSD or a waxing and waning symptoms course of PTSD.

A further study by Cordova *et al.* (2000) looked at the symptom structure of PTSD in cancer survivors. One hundred and forty-two breast cancer survivors were assessed using the PCL-C. Confirmatory factor analysis was applied to the data to evaluate the extent to which the symptoms reported were replicated in the symptom structure implied by DSM-IV. A moderate fit was found providing support for the DSM-IV clustering of PTSD symptoms i.e. re-experiencing, avoidance/numbing and arousal symptoms, and for the validity of cancer-related PTSD. This provides evidence contrary to Baider *et al.* (1997) who suggested PTSD was not an appropriate diagnosis in this population.

Jacobsen *et al.* (2002) conducted a longitudinal study looking at prevalence and predictors of PTSD in 70 bone marrow transplant recipients. The PCL-C was used to assess PTSD symptoms and 9% of the sample met DSM-IV criteria for cancer-related PTSD. Medical and demographic variables showed no significant relationship with PTSD symptomatology. However, avoidance-coping strategies and social support were found to account for at least 14% of the variability in PTSD symptom severity. As a result of the longitudinal nature of the study, the authors suggest that these findings support the view that avoidance-coping and social support, play a causal role in the development of PTSD in cancer patients. This study corroborates the findings of previous authors (Cordova *et al.*, 1995; Green *et al.*,

1998) regarding the prevalence of PTSD in bone marrow transplant patients. However, the findings regarding the relationship between demographic variables, such as age and education, and PTSD severity, are contrary to other authors (Cordova *et al.*, 1995; Jacobsen *et al.*, 1998; Tjemsland *et al.*, 1998). This may be a result of lack of power due to the low participant numbers with respect to the use of multiple regression to analyse the data. This study has, however, taken an important step, going beyond cross-sectional studies of prevalence, to consider predictors of cancer-related PTSD.

Mundy *et al.* (2000) examined the prevalence of PTSD in two groups of breast cancer survivors. The first group had undergone ABMT and the second group had received conventional treatments such as surgery, chemotherapy and/or radiotherapy. None of the BMT group developed PTSD as a result of their treatment experience. No current PTSD was found in either group. This differs from findings of other authors (Cordova *et al.*, 1995; Green *et al.*, 1998) and may be a result of the small sample size in this study.

These studies suggest that some cancer patients do experience symptoms that meet the criteria for DSM-IV diagnosis of PTSD. They also highlight that a large number of patients who do not meet the diagnostic criteria for PTSD suffer sub-dromal levels of PTSD symptomatology and therefore experience psychological distress as a result of their cancer experience. Shorter time since treatment completion, greater traumatic history prior to cancer, less social support, younger age and more advanced disease are all factors that have been associated with increased PTSD symptomatology (Andrykowski and Cordova, 1998; Cordova *et al.*, 1995). Generalisations should be cautious as the majority of these studies have been carried out on breast cancer patients and thus the majority of the sample

populations are female. Many of the studies have also been carried out by telephone interview or using self-report measures which may reduce the reliability of their results. Further studies which address some of these issues are required.

DESCRIPTION OF FEAR OF RECURRENCE STUDIES

Excluded Studies

Thirteen studies were retrieved relating to fear of recurrence in adult cancer survivors. However, 11 did not meet criteria for inclusion in this review. Six of the studies were excluded due to the use of an un-standardised assessment of fear of recurrence (Fredette, 1995; Kiebert *et al.*, 1993; Lasry and Margolese, 1992; Noguchi *et al.*, 1993; Thoñnas *et al.*, 1997; Vickberg, 2001). Three studies were excluded as they were narrative or case-studies (Aufdenkamp, 1997; Hurt *et al.*, 1994; O'Neill, 1975) and 2 studies were excluded as they included patients who were not free from disease or because their criteria were not clearly reported in their study (Herschbach *et al.*, 2000; Hilton, 1989).

Included Studies

As can be seen the quality of studies in this area was poor in main due to a paucity of standardised measures of this construct. There were only two studies that met the quality standards of this review (Mast, 1998; Northouse, 1981).

Design

Both studies were cross-sectional.

Setting

Both studies were conducted in the USA.

 Insert Table 2 about here

STUDIES OF FEAR OF RECURRENCE AND CANCER SURVIVORS

Fear of cancer recurrence has been highlighted within the cancer literature on numerous occasions (Hilton, 1989; Hurt *et al.*, 1994; Lee-Jones *et al.*, 1997; O'Neill, 1975). However, very little research has been carried out in this area. Most of the published information is based on expert opinion rather than empirical evidence. No study to date has examined the prevalence of significant levels of fear of recurrence, although one author has suggested it is almost universally present at some level (O'Neill, 1975).

Empirically based studies have examined factors that mediate fear of recurrence and its possible role in the psychological distress experienced by cancer patients and cancer survivors (see Table 2). Northouse (1981) conducted a study examining the relationship between significant others and levels of fear of recurrence in 30 mastectomy patients who were in cancer remission. Significant others were defined as those to whom the subject could speak about mastectomy-related concerns. The Fear of Recurrence Questionnaire

was designed and standardised as part of this study. There was a strong negative relationship between the number of significant others a patient had and their level of fear of recurrence. However, this study had a small sample size and only included female patients so the results should be considered with caution when considering a general cancer population.

Mast (1998) conducted a study of 109 breast cancer survivors who were 1-6 years post-treatment. Data were gathered regarding symptom distress (Symptom Distress Scale; SDS), fear of recurrence (Fear of Recurrence questionnaire; FRQ), illness uncertainty (Mishels Uncertainty Illness Scale; MUIS), positive appraisal (Growth Through Uncertainty Scale; GTUS) and emotional distress (Profile of Mood States-Short Form; POMS). Older women were found to experience less fear of recurrence than younger women. Fear of recurrence was found to be linked to emotional distress in some women.

These studies suggest that fear of recurrence can result in considerable emotional distress. To date mediators of fear of recurrence have been identified as age and number of significant others in the patient's life. Both these studies consider female only populations and therefore generalisations must be cautious (Mast, 1998; Northouse, 1981).

DESCRIPTION OF SENSE OF COHERENCE STUDIES

Excluded Studies

Twelve studies were retrieved that related to sense of coherence in cancer survivors. However, seven of these studies did not meet the criteria for inclusion in this study. Two studies were excluded as they considered patients who were newly diagnosed or who were still receiving treatment (Mullen *et al.*, 1993; Ramfelt *et al.*, 2000). Three studies were excluded as some participants were unclear about their diagnosis (Forsberg and Bjorvell, 1996; Forsberg *et al.*, 1996; 1997). One study was excluded as it was unclear whether all patients in the study were cancer patients (Nordstrom and Lutzen, 1995). One study was excluded as it was unclear whether all patients were in remission at the end of the study therefore could be considered survivors (Persson *et al.*, 2001).

Included Studies

Five studies met the quality criteria for inclusion in this study (Boman *et al.*, 1999; Gritz *et al.*, 1990; Persson *et al.*, 1997; Wettergren *et al.*, 1997; Wettergren *et al.*, 1999).

Design

Three of the studies were prospective longitudinal studies (Boman *et al.*, 1999; Wettergren *et al.*, 1997; Wettergren *et al.*, 1999) and two studies were cross-sectional (Gritz *et al.*, 1990; Persson *et al.*, 1997).

Setting

Four studies were conducted in Sweden (Boman *et al.*, 1999; Persson *et al.*, 1997; Wettergren *et al.*, 1997; Wettergren *et al.*, 1999) and one study (Gritz *et al.*, 1990) was conducted in the USA.

STUDIES OF SENSE OF COHERENCE AND CANCER SURVIVORS

Few studies have considered the role of sense of coherence in the psychosocial adjustment of cancer patients and only five studies met the inclusion criteria of this review (Table 3). Gritz *et al.* (1990) reported a study of 34 testicular cancer survivors and their spouses, who were screened using the Profile of Mood States (POMS), the CES-D, the Sense of Coherence Scale and Family Environment Scale. Both patients and spouses had similar levels of mood disturbance as measured by the POMS and CES-D. There was a statistically significant negative correlation between these scores and both the patients and the spouses scores on the SOC scales.

Perssons *et al.* (1997) studied 54 survivors of acute leukaemia or highly malignant lymphoma. Each participant completed a qualitative questionnaire and the Sense of Coherence scale. SOC was found to have no relationship to the degree of problems or the view of care received during the treatment phase. There was however a statistically significant negative correlation between SOC and existential problems such as worry about recurrence, worry about the future and anxiety, sensitivity to infections and the need for counselling.

Wettergren *et al.* (1997) carried out a prospective longitudinal study examining 12 participants who had undergone autologous bone marrow transplantation. They were assessed pre-transplant, 2-6 months post-transplant and 8-12 months post-transplant using the EORTC Quality of Life Questionnaire (QLQ-C30), the Hospital Anxiety and Depression (HAD) scale and the Sense of Coherence (SOC) scale. SOC scale scores and the EORTC QLQ-C30 scores were not statistically significantly related except for fatigue and appetite loss pre-treatment. There was no statistically significant relationship found between SOC scale scores and the scores on the HADS. This differs from Gritz *et al.*'s (1990) finding of a relationship between mood and SOC. It is possible that this study has failed to find a relationship due to the small study numbers and resulting lack of power.

Boman *et al.* (1999) examined two models of care in women who had completed treatment for breast cancer. Their perceived well-being was determined using a "study-specific questionnaire" and the sense of coherence scale. Group 1 received established care and Group 2 received continuity care. The SOC Scale scores of those in Group 2 were significantly higher than the scores of those in Group 1. Pre-treatment, those with a higher SOC had more trust in their surgeon and greater perceived general health. Those who were in Group 2 had better mental well-being one year after surgery compared with those in Group 1. The authors comment that it is possible this result was mediated by Group 2 having a higher SOC.

A recent study by Wettergren *et al.* (1999) examined the role of sense of coherence in cancer patients with PTS symptomatology. No statistically significant relationship was found between sense of coherence and PTS symptomatology, but the results were in the

direction that suggested that those with a high sense of coherence are likely to have fewer PTS symptoms as compared with those who have a low sense of coherence. The authors comment that the failure to find a statistically significant result may be due to the small sample size.

These studies suggest that sense of coherence may have a mediating and moderating role in the psychological distress experienced by cancer patients. Many of the studies carried out in this area have however had small sample sizes and further research on bigger patient samples is needed.

CONCLUSION

Overall the quality of the literature in this area was poor, with the majority of studies receiving a VIa rating on the quality criteria. Taking this into consideration these studies suggest that PTSD can result from the diagnosis and treatment of cancer and that the symptom structure of this disorder is similar in cancer survivors as it is in those who have other traumatic experiences. There is therefore no reason for future studies not to examine PTSD resulting from cancer within the general theoretical models of PTSD. This review also highlights that fear of recurrence is a recognised concept within cancer populations but that to date few stringent studies have been carried out to measure its psychological impact in cancer survivors. No studies as yet have examined the relationship between fear of recurrence and PTS symptomatology in cancer survivors in spite of clear theoretical links. Sense of coherence has been shown to mediate and moderate psychological distress in

cancer patients, particularly in relation to mood and emotional well-being. A preliminary study has been carried out examining the relationship between PTS symptomatology and sense of coherence but due to small sample size it was not conclusive (Wettergren *et al.*, 1999).

Given Ehlers and Clarks (2000) model of PTSD, and the literature reviewed in the current paper, it is possible that a link exists between PTS symptomatology caused by cancer and both fear of recurrence and sense of coherence. If this were the case, assessment of fear of recurrence and sense of coherence could allow for early intervention with those who are diagnosed with cancer and are at risk of development of PTS symptomatology. However, this relationship has not yet been empirically examined. Further work in this area may have implications for prevention of PTSD in response to cancer.

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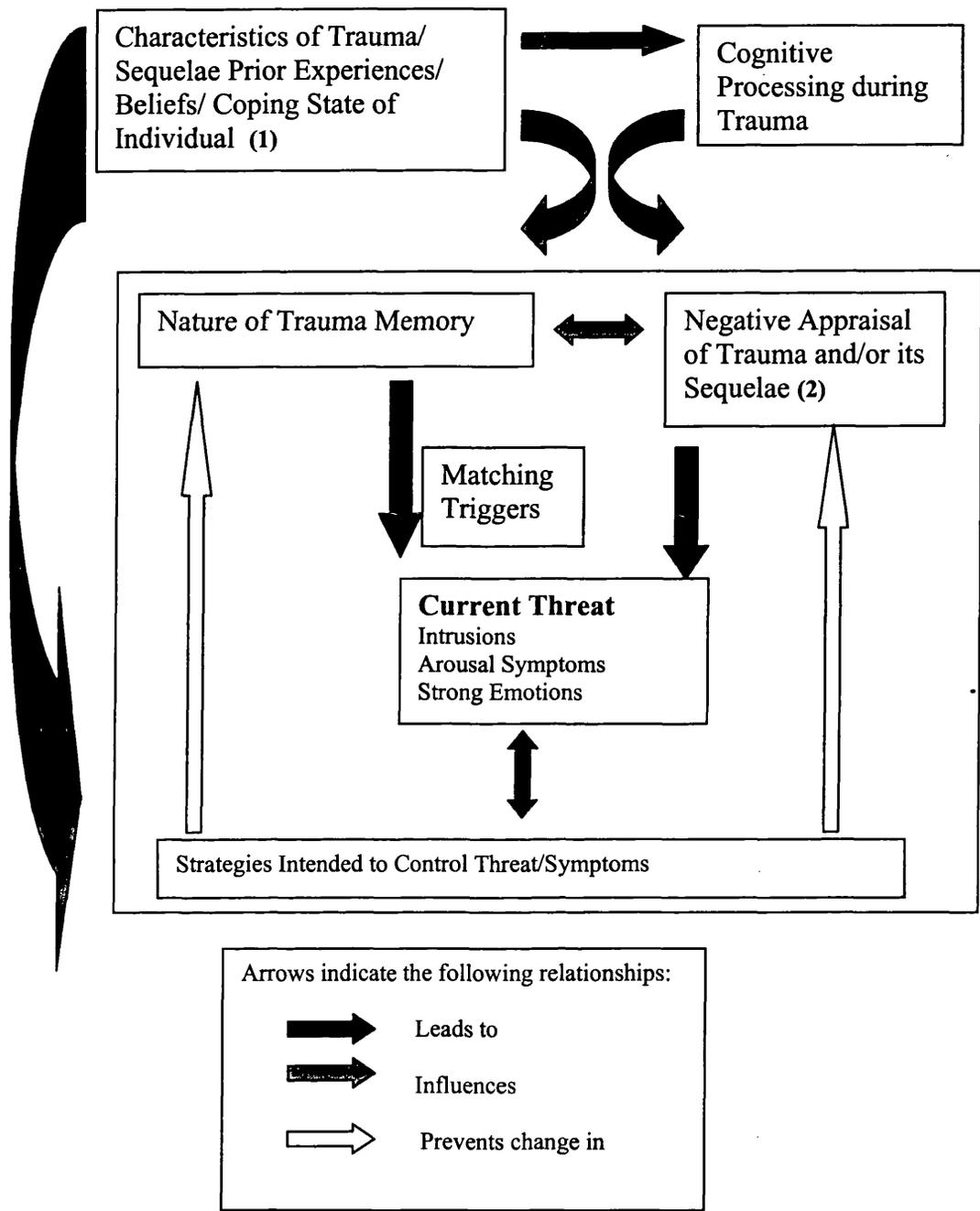


Fig. 1. A Cognitive Model of PTSD (Ehlers and Clark 2000)

Table 1: Summary of studies assessing PTSD in cancer patients.

Investigator	Design	Study Quality	Target Group	Sample Characteristics	PTSD assessment method	PTSD	Study limitations
Mundy et al. (2000)	Cross-sectional	IVb	Women diagnosed with breast cancer. Group 1: Those who had undergone autologous bone marrow transplants and who were disease free at time of assessment. (n=17) Group 2: Those who had been treated for breast cancer but not with BMT and were disease free at time of assessment. (n=20)	Group 1: mean age = 43.3 years; mean months post-treatment = 10.4 months. Group 2: mean age = 50.2 years; mean months post-treatment = 43.3 months.	SCID for DSM-IV ¹	No current PTSD was found in either group. None of those who had undergone bone marrow transplants developed PTSD as a result of treatment. PTSD was most likely to develop at the time of diagnosis.	Women only; low numbers.
Andrykowski et al. (2000)	Prospective longitudinal; initial telephone interview and follow-up 1 year later.	Va	Women diagnosed with Stages 0-IIIa breast cancer, 3-60 months post-completion of all primary breast cancer therapy, and in continuous remission since conclusion of primary cancer therapy. (n=46)	Mean age = 56.4 year (SD=9.7); mean months post-treatment = 29.8 months (SD=14.8). Dx: 9% had Stage 0; 59% had Stage I; 28% had Stage II; 4% had Stage IIIa at time of diagnosis.	PCL-C ²	PTSD symptoms did not diminish over time.	Telephone interview; women only;

¹ SCID for DSM-IV: Structured Clinical Interview for DSM-IV

² PCL-C: Posttraumatic Stress Disorder Checklist-Civilian Version

Cordova et al. (2000)	Cross-sectional; patients were identified from two centres in the Kentucky and Florida and data gathered by telephone interview or mail survey.	Via	Women diagnosed with stages 0-IV breast cancer who had completed all treatment. (n=142)	Kentucky: mean age = 56.4 years (SD = 10.4); mean months post-treatment = 35.6 (SD = 17.4); Florida: mean age = 44.4 (SD = 5.6); means months post-treatment = 19.4 (SD = 15.9); Combined centres: Dx: n=8 had stage 0, n=52 had stage I, n=44 had stage II, n=22 had stage III and n=16 had stage IV breast cancer at Dx.	PCL-C	8.5-12.7% met criteria for current PTSD. A further 12.7% met criteria for "partial PTSD" (i.e. met criteria for two of the three symptoms clusters). Symptoms reported moderately replicated the symptom structure implied by DSM-IV, providing support for the validity of cancer-related PTSD.	Telephone interview, women only.
Widows et al. (2000)	Cross-sectional; mail survey.	Via	Patients who had completed allogenic or autologous bone marrow transplantation and were disease free at most recent examination. (n=102)	Males = 23; Female = 79; mean age = 45.02 (SD = 10.65); mean months post-transplant = 20.42 (SD = 14.27); 49% had breast cancer, 15% had non-Hodgkin's lymphoma, 10% had chronic myelogenous leukaemia, 26% other Dx.	SCID-I/NP; PCL-C; Trauma Experience Questionnaire.	5% of BMT recipients met DSM-IV criteria for current diagnosis of cancer-related PTSD.	
Jacobsen et al. (1998)	Cross-sectional; mail survey.	Via	Women who had completed autologous bone marrow transplantation for breast cancer and were free from disease at most recent examination. (n=44)	Mean age = 44.39 (SD = 5.64); mean months post-transplant = 19.36 (SD = 15.86); at time of transplant Dx: 30% had stage II, 37% had stage III, 33% had stage IV.	PCL-C	12-19% of sample were likely to meet DSM-IV criteria for current PTSD	Women only.

Andrykowski et al. (1998)	Cross-sectional, telephone interview.	V1a	Women diagnosed with stage I, II or III-A carcinoma of the breast who had completed all treatment and were in remission. (n=82)	Mean age = 56.6 years (SD = 10.5); mean months post-treatment = 37.3 (SD = 16.4); Dx: 54% had stage I, 32% had stage II, 6% had stage III-A.	PCL-C; part of SCID-NP-PTSD module.	6% of the sample met criteria for current PTSD, with a further 4% having lifetime PTSD. The authors concluded that diagnosis and treatment of cancer can precipitate PTSD. The PCL-C was found to be a cost-effective screening tool for this population.	Telephone interview, women only.
Andrykowski and Cordova (1998)	Cross-sectional, telephone interviews.	V1a	Women diagnosed with stage I, II or III-A carcinoma of the breast who had completed all treatment and were in remission. (n=82)	Mean age = 56.6 years (SD = 10.5); mean months post-treatment = 37.3 (SD = 16.4); Dx: 54% had stage I, 32% had stage II, 6% had stage III-A.	PCL-C; part of SCID-NP-PTSD module.	5% of sample met criteria for current PTSD diagnosis. A further 5-15% reported sub-dromal levels of PTSD symptoms.	Telephone interview, women only.
Green et al. (1998)	Cross-sectional, interview study.	V1a	Women diagnosed with Stage I or Stage II node-negative breast cancer who were 4-12 months post-cancer treatment. (n=160)	Mean age = 53.40 years (SD=9.66); mean months post-treatment = 6.5 months.	SCID, THQ ³ , IES ⁴ , SIE ⁵ .	Three of the women had a post cancer PTSD diagnosis. PTS symptomatology were however much more common with 36% of the women reporting at least one symptom.	Women only.

³ THQ: Trauma History Questionnaire

⁴ IES: Impact of Events Scale

⁵ SIE: Stressful Illness Experience Scale

	IVa	IVb	IES	None of the patients were diagnosed as having PTSD. Across all groups, intrusions were found to explain 30% of the variability in the patients' psychological distress. Concluded that cancer patients did not suffer from PTSD as defined by DSM-IV but showed cognitive styles associated with PTSD. Suggested diagnosis of adjustment disorder with intrusive symptoms.	Women only.
Baider et al. (1997)	Cross-sectional; three groups comparing the effect of pre-cancer trauma on coping with cancer.	Women diagnosed with stage I or Stage II breast cancer who were in follow-up. (n=283)	Group A (n=61), 31 Holocaust survivors and 30 matched controls not traumatised in the past. Group B (n=116), immigrants from the former Soviet Union who had been in Israel for an average of 2.5 years. Group C (n=106) no previous trauma prior to cancer diagnosis and treatment.	None of the patients were diagnosed as having PTSD. Across all groups, intrusions were found to explain 30% of the variability in the patients' psychological distress. Concluded that cancer patients did not suffer from PTSD as defined by DSM-IV but showed cognitive styles associated with PTSD. Suggested diagnosis of adjustment disorder with intrusive symptoms.	Women only.
Alter et al. (1996)	Cross-sectional with matched community-based control group.	Women currently in active follow-up who were receiving no active treatment; control group were demographically matched and living in the same geographical area. (n=27)	Mean age of cancer survivors = 54 years (+/- 11); mean years post-treatment = 4.6; mean years post-Dx = 5.4; mean age of control group = 48 years (+/- 6)	4% of survivors met criteria for current PTSD and 22% met criteria for lifetime PTSD. None of the control group met PTSD criteria.	Women only; low numbers.
Jacóbsen et al. (2002)	Prospective Longitudinal	Patients who had completed allogenic or autologous bone marrow transplantation and were disease free at most recent examination. (n=70)	Mean age = 48 years (SD=9); mean months post-discharge=6.9 (SD1.2); breast cancer = 67%, leukaemia = 12%, multiple myeloma = 13%, lymphoma = 8%.	6-9% of participants met DSM-IV criteria for cancer-related PTSD. Avoidance-coping and social support found to predict PTSD severity.	Low numbers for the type of analysis carried out.

Cordova et al. (1995)	Cross-sectional; telephone interviews of patients attending a breast care centre in the USA.	V1a Women diagnosed with stage I, II or III-A carcinoma of the breast that had completed primary breast cancer therapy. (n=55)	Mean age = 55.5 years (SD = 9.7); mean months post-treatment = 30.5 (SD = 16); Dx: 62% had stage I, 34% had stage II, 4% had stage III-A.	IES; PCL-C	5% to 10% of subjects met DSM-IV criteria for current PTSD.	Telephone interview; women only.
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Table 2: Summary of studies assessing fear of recurrence in cancer patients.

Investigator	Design	Study Quality	Target Group	Sample Characteristics	Fear of Recurrence Assessment Method	Fear of Recurrence	Study limitations
Mast (1998)	Cross-sectional; in-person interview.	VIa	Women, diagnosed with stage I-III non-metastatic breast cancer, who were 1-6 years post-treatment. (n=109)	Mean age = 60 (SD = 12.90); mean months since treatment = 39.8 (SD = 16.0).	Fear of Recurrence Questionnaire; Mishel's Uncertainty in Illness Scale; Growth Through Uncertainty Scale	Fear of recurrence was related to emotional distress, even years after treatment.	Women only.
Northouse (1981)	Cross-sectional; in-person interview.	VTb	Women diagnosed with stages I-III breast cancer, who had received adjuvant treatment and who were in cancer remission. (n=30).	Mean age = 54 (SD = 10.5); mean time since surgery = 3 years (SD = 1.04)	Fear of Recurrence Questionnaire (designed and standardised as part of the study)	Their was a strong relationship between the number of significant others an individual had and their level of fear of recurrence.	Women only; low numbers.

Table 3: Summary of studies assessing sense of coherence in cancer patients.

Investigator	Design	Study Quality	Target Group	Sample Characteristics	Sense of Coherence Assessment Method	Sense of Coherence	Study limitations
Boman et al. (1999)	Prospective longitudinal; interview before breast surgery, 10-14 days after surgery and 1 year after surgery.	IIIb	Two groups of breast cancer patients. Group 1; Established care: Pre-surgery n=29, 1 st follow-up n=27, 2 nd follow-up n=23. Group 2; Continuity care: Pre-surgery, 1 st follow-up, and 2 nd follow-up n=115.	Group 1: Mean age = 57 (SD=13) Group 2: Mean age = 59 (SD=11)	SOC ⁶ scale	Stronger SOC was linked to better emotional well-being pre-surgery, post-surgery and one year post-surgery, better general health pre-surgery, and stronger feelings of trust in the surgeon.	Women only; low numbers.
Wettergren et al. (1999)	Prospective longitudinal; interview one week before ASCT (n=20) and at 2-6 months post-treatment (n=14) and at six months post-follow-up (n=12).	Vb	Patients who had received autologous stem cell transplantation for a haematological malignant disorder. (n=20).	Males = 12; females = 8; mean age = 37 (range 17-54).	SOC scale	No significant relationship was found between sense of coherence and PTS symptomatology.	Low numbers
Pérsons et al. (1997)	Cross-sectional; mail survey. (n=54)	VIa	Patients who had been diagnosed with acute leukaemia or highly malignant lymphoma and who's disease was in remission at the time of assessment.	Males = 28; females = 26. Mean age = 62.8 (SD = 15.7)	SOC scale	SOC had no relationship to the degree of problems or the view of care received. There was a negative relationship between SOC and current existential problems, sensitivity to infections and need for help and counselling.	

⁶ SOC Scale: Sense of Coherence Scale

Wettergren et al. (1997)	Prospective longitudinal; interview one week before ABMT (n=20) and at 2-6 months post-treatment (n=14) and at 8-12 months follow-up (n=12).	Vb	Patients who had received autologous bone marrow transplantation for a hematological malignant disorder. (n=20).	Males = 12; females = 8; median age = 36 (range 17-54).	SOC scale	Lower SOC was associated with more reported fatigue and appetite loss pre-ABMT. There was no significant relationship between SOC and anxiety and depression.	Low numbers.
Gritz et al. (1990)	Cross-sectional; Interview Study (patients n=34; spouses n=34)	V1a	Patients diagnosed with either seminomatous or non-seminomatous testicular cancer who had completed treatment between 1 and 7.5 years previously and their spouses.	Patients: mean age 37.7 years. Spouses: mean age 35.6 years.	SOC scale	There was a significant relationship between high sense of coherence and high mood as measured by the CES-D and the POMS.	Male only.

CHAPTER 3

MAJOR RESEARCH PROJECT PROPOSAL

Fear of Recurrence, Sense of Coherence and Posttraumatic Stress Disorder in Haematological Cancer Survivors.

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Prepared in accordance with the guidelines (Appendix 3.01)

SUMMARY

Given the incidence of psychological distress found among people with cancer (Zabora *et al.*, 2001) gaining an understanding of psychosocial adjustment to cancer should be a central concern of clinicians working in this field (Brennan, 2001). In patients with haematological cancer, treatment procedures are particularly intensive and can result in prolonged distress even after completion of treatment (McQuellon *et al.*, 1998). In acute leukaemia patients high levels of distress have been found up to and more than one year after treatment (Lesko, 1990).

Since the modification of DSM-III to DSM-IV (APA, 1994) cancer has been recognised as a traumatic event capable of precipitating posttraumatic stress disorder (PTSD). Fear of recurrence has been recognised as a concept within cancer literature over the last twenty-five years (Metzger *et al.*, 1983; Weed and Holland, 1977). Current literature suggests that PTSD only occurs in individuals if they process their traumatic event in a way that produces a sense of serious current threat (Ehlers and Clark, 2000). This suggests that those cancer survivors with a high fear of recurrence will also exhibit high posttraumatic stress symptomatology (PTSS).

However, leukaemia survivors do not all experience the same levels of distress. Antonovsky (1979; 1987) has outlined a construct called sense of coherence (SOC) that explains why some people adapt well in situations that result in psychological morbidity for others. This paper will therefore provide further understanding of the process of adjustment by examining the relationship between PTSS, fear of recurrence, and sense of coherence in leukaemia survivors.

INTRODUCTION

The modification of DSM-III to DSM-IV (APA, 1994) allowed the inclusion of life-threatening illness, including cancer, as an event capable of precipitating PTSD. A typical response to cancer diagnosis and treatment includes feelings of fear, horror and helplessness (Smith *et al.*, 1999b). Intrusive thoughts and nightmares about treatment and attempts to avoid reminders of both diagnosis and treatment can follow. These responses are typical of those experienced in PTSD. However, cancer does differ in some ways from other trauma. DSM-IV PTSD diagnostic criteria demand “actual or threatened death or serious injury” (APA, 1994). In cancer this can vary considerably both in immediacy and degree of life threat. The significance of the intrusive thoughts experienced by cancer survivors may therefore relate more to threat located in the future than in the past (Brennan, 2001).

Studies to date report estimated rates of PTSD from 1.9% (Green *et al.*, 1998) to 12% (Tjemsland *et al.*, 1998) in breast cancer survivors. These rates are in-line with the rates reported by other high-risk populations (Tjemsland *et al.*, 1998). However there is also a growing body of research that suggests that the diagnosis and treatment of cancer may lead to the persistence of PTSS in many patients without necessarily leading to the full syndrome (Brennan, 2001; Cella *et al.*, 1990; Cordova *et al.*, 1995).

Although the cancer survivor may experience an initial sense of relief on completion of treatment, they often go on to have feelings of intense anxiety as a result of the reduced involvement of the medical team and the unpredictability that sets cancer apart from other illnesses (Hurt *et al.*, 1994). Dunkel-Schetter *et al.* (1992) found that fear and uncertainty about the future were the most commonly identified cancer-related problems in cancer

survivors. Lee-Jones *et al.* (1997) propose a model of fear of recurrence that states that people develop a representation of their illness based on personal experiences, myths and the media. Consequently individuals produce very different representation of their illness, leading to varied responses to both cancer diagnosis and level of concern about fear of recurrence. Fear of recurrence is, however, thought to be almost universally present (O'Neill, 1975; Somerfield *et al.*, 1999).

However, many cancer survivors can experience positive growth as they adjust to changes brought about by their illness (Brennan, 2001). Antonovsky (1979; 1987) proposed a salutogenic orientation asserting that the secret of health is adaptive coping, moderated by 'generalised resistance resources'. These resources include wealth, social support, ego strength and coping strategies and are seen as leading to life experiences that promote the development of a strong sense of coherence (SOC) or a way of seeing the world that facilitates successful coping (Antonovsky, 1993). Antonovsky implicates SOC in the management of everyday stressors. A strong SOC is therefore implicated in maintaining and increasing an individual's health status.

A paper by Mullen *et al.* (1993) examined cancer patients and their spouses found that SOC was the only significant predictor of psychological stress. One study has considered the role of SOC in cancer patients with PTSS. Although no significant correlation was found the findings fell in the expected direction with those with a higher SOC having less PTSS (Wettergren *et al.*, 1999).

A number of models of PTSD have been presented based on cognitive, cognitive-behavioural and behavioural theories. Ehlers and Clark (2000) have proposed a cognitive

model of persistent PTSD that proposes that 'persistent PTSD occurs only if individuals process the traumatic event and/or its sequelae in a way that produces a sense of serious current threat'.

Fear of recurrence appears to fit with Ehlers and Clarks' (2000) model in that it represents a belief that cancer survivors have a sense of serious current threat and a belief that their trauma is not time-limited. This would suggest that those who have a greater fear of recurrence are more likely to suffer PTSS. Antonovsky's model further adds to this proposing that those who have a high SOC are less likely to have fear of recurrence and are likely to have less PTSS. This can be concluded, as based on Antonovsky's model, their SOC will provide them with adaptive coping strategies that will allow them to manage this stressful event.

In this study those surviving haematological malignancies will be considered. These individuals often undergo very intensive therapy, including high dose chemotherapy, total body irradiation and autologous stem cell transplantation (Wettergren *et al.*, 1999). Such intensive therapy is often associated with psychological morbidity both during treatment and after completion of treatment (Lesko, 1990; McQuellon *et al.*, 1998). Very few studies to date have examined issue's relating to PTSS in this population.

AIMS AND HYPOTHESES

Aims

To investigate the relationship between fear of cancer recurrence and the degree of PTSS experienced by cancer survivors, and to explore the role sense of coherence plays in this

relationship. A secondary aim of the study will be the translation and standardisation of the Fear of Progression Questionnaire from German into English.

Hypotheses

- 1) It is therefore hypothesised that those who have a high fear of recurrence will have higher PTSS.
- 2) Those with a high SOC will show fewer PTSS.
- 3) Those with high SOC will show lower fear of recurrence.

METHOD AND DESIGN

Participants

Participants will be recruited from post-treatment outpatient follow-up clinics in Glasgow Royal Infirmary; Western Infirmary, Glasgow; and Crosshouse Hospital, Kilmarnock.

Participants will be adults (aged 18+), who are leukaemia survivors receiving no active treatment and attending a follow-up clinic. They will have been in continuous remission since primary completion of treatment and be at least 3 months post-completion of treatment. Worden and Weisman (1977) found that cancer patients' distress does not peak until 2 to 3 months following completion of treatment. Exclusion criteria will include a history of chronic illness and previous experience of life threatening accidents. Patients who have a prior history of traumatic occurrences may have had existing posttraumatic symptomatology prior to their cancer diagnosis and treatment. History of previous psychological disorder is a predictor for PTSD, therefore those with a prior history of psychological disorder will be excluded from the study.

Measures

Posttraumatic stress disorder

A number of scales have been produced for assessment of PTSD and its symptoms. Due to the time factor involved structured clinical assessments (e.g. the Structured Clinical Interview for DSM-IV) (First *et al.*, 1995), will not be considered for this study. Brief symptom inventories include the Impact of Events Scale (Horowitz *et al.*, 1979), and the Brief Symptom Inventory (Derogatis, 1985). These have been excluded due to a number of reasons including their exclusive focus on a specific type of stressor and/or their failure to assess the full range of PTSD symptoms.

PTSS will therefore be measured using two checklists, the PTSD Checklist-Civilian Version (PCL-C) (Weathers *et al.*, 1991) which has been used extensively on cancer populations and the Impact of Events Scale-Revised (Weiss and Marmar, 1997). The PTSD Checklist-Civilian Version (Appendix 3.02) is a brief 17-item inventory of PTSD-like symptomatology. This checklist has been designed specifically to assess traumatic experiences encountered in the course of everyday living. The PCL-C provides a continuous score (17-85) based on the quantity and severity of symptoms. This allows it to assess gradations in PTSD symptomatology. Reliability for this scale has been indicated by Cronbach's Alpha coefficients ranging from 0.89 (Smith *et al.*, 1999a) to 0.97 (Weathers *et al.*, 1993). Convergent validity has been shown by a strong correlation between the PCL and the Mississippi scale (0.93) (Keane *et al.*, 1988) and the Impact of Events Scale (0.90) (Weathers *et al.*, 1993). For the purposes of this study the words 'a stressful experience' on the questionnaire, have been changed to 'your cancer experience'

to increase the ease with which the questionnaire is understood and filled out. This alteration in wording is within the guidelines of the author.

The Impact of Events Scale-Revised (Weiss and Marmar, 1997) (Appendix 3.03) comprises the original 15 items from the original Impact of Events Scale (Horowitz *et al.*, 1979), with an additional seven items. Six of these items assess hyperarousal and one item parallels DSM-IV diagnostic criteria. A test-retest reliability coefficient of 0.91 has been reported, as have high internal consistency coefficients of the intrusion (Cronbach's alpha = 0.85), avoidance (Cronbach's alpha = 0.85) and hyperarousal (Cronbach's alpha = 0.94) subscales (Weiss and Marmar, 1997). Evidence for construct validity includes strong correlations among the three subscale scores, ranging from 0.74 to 0.87. This scale has not yet been used in this population.

Fear of Recurrence

A number of scales have been developed for the measurement of fear of recurrence (Easterling and Leventhal, 1989; Freidenbergs *et al.*, 1980; Greenberg *et al.*, 1997; Herschbach *et al.*, 2000; Kiebert *et al.*, 1993; Lasry and Margolese, 1992; Northouse, 1981). However, the majority of these scales were developed for use in America and require further validation and testing on British samples. It is proposed that three measures be used in this study. Northouse's (1981) Fear of Recurrence Questionnaire (Appendix 3.04) is a 22-item scale and has been shown to have reliability (Cronbach's alpha coefficient of 0.92) (Hilton, 1989) and content validity (Northouse, 1981). For the purposes of this study the word 'illness' on the questionnaire, has been changed to 'cancer' to increase the ease with which the questionnaire is understood and filled out. This alteration in wording is within the guidelines of the author. The more recent Fear of

Relapse/Recurrence Scale (Appendix 3.05), a five-item scale devised by Kornblith (Greenberg *et al.*, 1997), using a population of adult leukaemia survivors, has also been shown to have both reliability (Cronbach's alpha = 0.73) and validity (Greenberg *et al.*, 1997; Hill *et al.*, 1998). The third measure used will be the Fear of Progression Questionnaire (FOP-Q; Appendix 3.06) developed by Herschbach *et al.* (2000). This is a 43-item scale that has an internal consistency coefficient of 0.95 and test-retest reliability coefficient of 0.94. Although this scale has the highest reliability of the scales reviewed there is little evidence of validity with only evidence that the scale does not correlate with measures of anxiety. It is also not currently available in English, requiring translation and standardisation before reliability and validity of the scale in English can be determined. This will be carried out as part of the study.

Sense of Coherence

The Sense of Coherence Scale (SOC-S; Appendix 3.07) will be used to assess level of sense of coherence (Antonovsky, 1987). This scale consists of 29-items measured on a seven-point scale with two anchoring phrases for each item. Measures of reliability indicate good internal consistency (studies report Cronbach's alpha scores from 0.82 to 0.95), good test-retest reliability and validity (Antonovsky, 1987; Flannery *et al.*, 1994).

Design and Procedure

Participants will be recruited personally by the researcher from outpatient follow-up clinics in Glasgow Royal Infirmary and Western Infirmary, Glasgow and Crosshouse Hospital, Kilmarnock. The purpose of the study will be explained to the patients, they will be given an information sheet to read (Appendix 3.08) and asked if they have any questions. Following this, those who agree to participate in the study will be asked to sign a consent

form (Appendix 3.09). Those who give consent to participate in the study will receive a package that contains the questionnaires, a demographic data sheet, and a stamped, addressed envelope. They will either be given the option to complete the questionnaires in the outpatient clinic and leave it there, or complete it at home and return it by mail. Should caseness levels of distress be found communication will be made to the consultant and GP and advice will be given about onward referral. Caseness level of distress will be determined by a total score of 50 on the PCL-C (Weathers *et al.*, 1993).

Data analysis

Multiple regression analysis will be carried out on the data, for the following reasons. An ANOVA or t-test design could only have been achieved by use of the median split technique. This approach was discarded primarily because the dichotomising of the continuous variable, SOC, into high and low bivariant categories goes against the underlying concept of the construct (Antonovsky, 1979). Further to this, median split approaches result in loss of information, which underestimates the magnitude of the bivariant relationship and lowers the statistical power for detecting true effects (Maxwell and Delaney, 1993).

Power calculations

Definition of Endpoints

High fear of recurrence will predict high PTS symptomatology and high sense of coherence will predict low PTS symptomatology.

Fear of recurrence and sense of coherence will be correlated with the measure of PTSS. A simultaneous multiple regression will then be carried out to determine the relationship

between the dependent variable, PTSS, and the explanatory variables, fear of recurrence and sense of coherence.

High sense of coherence will predict low fear of recurrence.

Sense of coherence will be correlated with fear of recurrence. A single linear regression will then be carried out to determine the relationship between the dependent variable, fear of recurrence and the explanatory variable, sense of coherence.

A correlation coefficient of 0.42 would be considered to be clinically significant. With 34 subjects the study will have 80% power to detect a correlation of 0.42 at alpha 0.05 (using data from (Wettergren *et al.*, 1999). It is noted that a model derived from multiple regression is likely to be over optimistic with respect to the importance of each variable. Altman (1990) suggests that to avoid this no more than $n/10$ explanatory variables should be considered (where n is sample size). Therefore the sample size indicated in this case is large enough to allow the examination of both explanatory variables.

PRACTICAL APPLICATIONS

This study will increase our understanding of the psychological mechanisms of adjustment and the psychological stress experienced by those who undergo cancer diagnosis and treatment. In particular it may provide a means of identifying those who are at risk or vulnerable to the development of posttraumatic stress symptomatology at the time of their diagnosis and thus provide preventative intervention for these individuals. It will also provide further information and support for current theories on the mechanisms of the development of PTSD.

TIMESCALE

March/April 2001: Translation of German Questionnaire
May 2001: Ethics Applications Submitted
July/ August 2001: Begin data collection
March 2002: Complete data collection

ETHICAL APPROVAL

Ethical approval was obtained from the North Glasgow University Hospitals NHS Trust, West Ethics Committee (Appendix 3.10) and East Ethics Committee (Appendix 3.11), and Ayrshire and Arran Health Board Research Ethics Committee (Appendix 3.12).

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AMMENDMENTS TO STUDY

1. p7. In order to recruit sufficient numbers, Hodgkin's and non-Hodgkin's survivors were also recruited for the study. An amendment to the original ethics application to North Glasgow University Hospitals NHS Trust, West Ethics Committee was proposed and approved (Appendix 3.13). Approval of this amendment was not necessary for the other ethics committees as the applications had not been submitted at the time of the change in criteria, so original applications took account of this change.
2. p7. The exclusion criteria were relaxed in order to allow sufficient recruitment. Patients with previous psychological disorder, chronic illness and trauma history were all included in the study. Information regarding the presence of these factors was recorded along with other demographic information.

CHAPTER 4**MAJOR RESEARCH PROJECT PAPER****Fear of Recurrence, Sense of Coherence and Posttraumatic Stress Disorder in
Haematological Cancer Survivors.****Esther K. Black***University of Glasgow**Department of Psychological Medicine**Gartnavel Royal Hospital, Glasgow, G12 0XH, UK.*

Prepared in accordance with the guidelines for submission to *Psycho-Oncology*

(Appendix 4.1)

**Fear of Recurrence, Sense of Coherence and Posttraumatic Stress Disorder in
Haematological Cancer Survivors.**

Short Title: Fear of Recurrence, Sense of Coherence and PTSD in Cancer Survivors.

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***Request for reprints**

SUMMARY

The diagnosis and treatment of cancer has been shown to precipitate Posttraumatic Stress Disorder (PTSD) in some cancer survivors. However few studies have considered the links between cancer-related PTSD and theoretical models of PTSD. This study considers a cognitive model of PTSD by examining the relationship between sense of coherence, and fear of recurrence to posttraumatic stress symptomatology (PTSS) in haematological cancer survivors. Thirty-five participants completed the PTSD Checklist – Civilian Version (PCL-C), the Impact of Events Scale – Revised (IES-R), the sense of coherence scale and three measures of fear of recurrence. Three measures of fear of recurrence were included as no fear of recurrence measures had previously been assessed for reliability and validity on British populations.

Fourteen percent of the sample met DSM-IV diagnostic criteria for PTSD. A statistically significant relationship was found between fear of recurrence and PTSS suggesting that cancer-related PTSS may fit within the theoretical model of PTSD considered. Statistically significant relationships were also found between sense of coherence and fear of recurrence and PTSS, raising questions about the possibility of using this construct as a screening measure for vulnerability to PTSD. Further examination of factors affecting the onset, maintenance and treatment of PTSD in this population is required.

INTRODUCTION

Since the publication of the Diagnostic and Statistical Manual of the American Psychiatric Association – Fourth Edition (DSM-IV) (APA, 1994) cancer has been recognised as a traumatic event capable of precipitating Posttraumatic Stress Disorder (PTSD). Cancer differs from other traumas in both immediacy and degree of life threat. It therefore cannot be assumed that PTSD related to cancer fits within current models of PTSD, or that its symptom structure is the same. Studies to date report estimated rates of PTSD from 1.9% (Green *et al.*, 1998) to 12% in cancer populations (Tjemsland *et al.*, 1998). This can be compared to rates of 23% in those surviving road traffic accidents (Holeva *et al.*, 2001) and 16.6% in war veterans (Kusevic *et al.*, 1999). There is also a growing body of research that suggests the diagnosis and treatment of cancer may lead to the persistence of posttraumatic stress symptoms (PTSS) in some patients without necessarily leading to the full syndrome (Brennan, 2001; Cella *et al.*, 1990; Cordova *et al.*, 1995).

A number of models of PTSD have been presented over the years, which are based on cognitive, cognitive-behavioural and behavioural theories (Foa *et al.*, 1989; Horowitz, 1997; Janoff-Bulman, 1992). Ehlers and Clark (2000) have outlined a cognitive model of persistent PTSD that proposes that “persistent PTSD occurs only if individuals process the traumatic event and/or its sequelae in a way that produces a sense of serious current threat” (p. 320). This model differs from other models as it attempts to use cognitive theories of anxiety, rather than general cognitive theories, to explain the development and persistence of PTSD. Kangas *et al.* (2002) have proposed that cancer-related PTSD should be examined within the network model of PTSD (Brewin *et al.*, 1996), however, Ehlers and Clark’s (2000) model is considered particularly relevant to cancer populations due to its emphasis on cognitive theories of anxiety, which suggest that anxiety occurs as a result of

perceived impending threat. Cancer differs from other traumas not only in that it is a more protracted trauma than many, but also as cancer recurrence is a real possibility. As a result of this cancer survivors may have a heightened sense of impending threat.

Studies have shown that although cancer survivors may experience an initial sense of relief on completion of treatment, they often go on to have feelings of intense anxiety as a result of the unpredictability that sets cancer apart from other illnesses (Hurt *et al.*, 1994). Dunkel-Schetter *et al.* (1992) found that fear and uncertainty about the future were the most commonly identified cancer-related problems in cancer survivors. Fear of recurrence is thought to be almost universally present (O'Neill, 1975; Somerfield *et al.*, 1999). Lee-Jones *et al.* (1997) propose a model of fear of recurrence that states that people develop a representation of their illness based on personal experiences, myths and the media. This leads to a very varied response to both cancer diagnosis and the level of concern about fear of recurrence experienced by the individual. Fear of recurrence appears to relate to Ehlers and Clarks (2000) model, as it represents a perception of serious current threat and a belief that the trauma is not time-limited. This would suggest that those who have a greater fear of recurrence are more likely to suffer PTSS.

Many cancer survivors experience positive growth as they adjust to changes brought about by their illness, in spite of this fear of recurrence (Brennan, 2001). Antonovsky (1979; 1987) suggested a model that focuses on the origins of health (salutogenic orientation) rather than disease (pathogenic orientation). This model proposes that the key to good health is adaptive coping that is moderated by what he refers to as 'generalised resistance resources', which include wealth, social support, ego strength and coping strategies. These resources are seen as leading to life experiences that promote the development of a strong

sense of coherence (SOC) that is a way of seeing the world that facilitates successful coping (Antonovsky, 1993). A strong SOC is therefore implicated in the management of everyday stressors to maintaining and increasing an individual's health status.

Two studies have been found which examine SOC in cancer patients. Mullen *et al.*'s (1993) study examined the effects of spiritual resources, family strengths and sense of coherence on psychological stress in cancer patients and their spouses. The study found that SOC was the only significant direct predictor of psychological stress. One study has considered the role of SOC in cancer patients with PTSS (Wettergren *et al.*, 1999). No significant result was found between SOC and severity of PTSS. The authors highlight small study numbers and resulting lack of power as possible reasons for this result. These studies suggest that SOC may be a relevant mediator and moderator of stress in cancer patients but further examination is required.

In summary, Ehlers and Clark's model of PTSD (Ehlers and Clark, 2000) appears to apply to PTSD in cancer patients as it proposes that PTSD only occurs if the individual processes the trauma in a way that leads to a sense of serious current threat. Cancer recurrence could be perceived as an immediate threat and therefore, fear of recurrence could be described as a sense of serious current threat. The sense of coherence construct appears to provide an explanation for why, in spite of there being the possibility of recurrence in most cancer, some cancer patients do not develop PTSS.

This study will investigate the relationship between fear of cancer recurrence and the degree of PTSS experienced by haematological cancer survivors, and will explore the role sense of coherence plays in this relationship. A secondary aim of the study will be the

translation and standardisation of the Fear of Progression Questionnaire from German into English.

HYPOTHESES

- 1) Those with a high fear of recurrence will have higher PTSS.
- 2) Those with a high SOC will have less PTSS.
- 3) Those with high SOC will have a lower fear of recurrence.

METHOD

Participants

In this study those surviving haematological malignancies will be considered. These individuals often undergo intensive therapy, including high dose chemotherapy, total body irradiation and autologous stem cell transplantation (Wettergren *et al.*, 1999). Intensive therapy is often associated with psychological morbidity both during and after completion of treatment (McQuellon *et al.*, 1998)] and psychological distress, as measured by the Brief Symptom Inventory (Derogatis, 1985), has been found in between 33% and 38% of those suffering from haematological cancer (Zabora *et al.*, 2001).

Forty-eight participants who had undergone treatment for Hodgkin's lymphoma, non-Hodgkin's lymphoma or acute leukaemia were recruited to the study. Thirty-four participants completed the questionnaires at home and returned them by post, 14 completed the questionnaires while in the out-patient clinic. Five participants were excluded, either because they were found not to meet the inclusion criteria on interview with the researcher, or because their verbal reports of their difficulties and concerns did not

correspond with their questionnaire responses thus their data were not considered reliable. A further eight participants did not return their questionnaires. Thirty-five participants were therefore included in the data analysis.

Measures

Posttraumatic stress symptomatology

1. PTSD Checklist-Civilian Version (PCL-C) (Weathers *et al.*, 1991)

The PCL-C is a 17-item inventory of PTSD symptomatology. The PCL-C provides a continuous score (17-85) based on the quantity and severity of symptoms allowing it to assess gradations in PTSD symptomatology. Reliability for this scale has been indicated by Cronbach's Alpha coefficients ranging from 0.89 (Smith *et al.*, 1999) to 0.97 (Weathers *et al.*, 1993). Convergent validity has been shown by a strong correlation between the PCL and the Mississippi scale (0.93) (Keane *et al.*, 1988) and the Impact of Events Scale (0.90) (Weathers *et al.*, 1993). For the purposes of this study the words 'a stressful experience' on the questionnaire, was changed to 'your cancer experience' to aid understanding. This alteration is within the guidelines of the author (Weathers *et al.*, 1993). There are currently no data available on the validity of this change in wording. This scale has been used extensively on cancer populations.

2. The Impact of Events Scale-Revised (Weiss and Marmar, 1997)

This is a 22-item scale for which a test-retest reliability coefficient of 0.91 and high alpha coefficients for intrusion (Cronbach's alpha = 0.85), avoidance (Cronbach's alpha = 0.85) and hyper arousal (Cronbach's alpha = 0.94) subscales (Weiss and Marmar, 1997) have been reported. Evidence for construct validity includes strong correlations among the three

subscale scores, ranging from 0.74 to 0.87. No studies to date have been found that have used this scale on this population.

Fear of Recurrence

A number of scales have been developed for the measurement of fear of recurrence (Easterling and Leventhal, 1989; Freidenbergs *et al.*, 1980; Greenberg *et al.*, 1997; Herschbach *et al.*, 2000; Kiebert *et al.*, 1993; Lasry and Margolese, 1992; Northouse, 1981). However, the majority of these scales were developed for use in America and require further validation and testing on British samples. It is proposed that the three measures with the highest reliability and validity be used in this study.

1. Fear of Recurrence Questionnaire (Northouse, 1981)

This is a 22-item scale that has been shown to have reliability (Cronbach's alpha coefficient of 0.92) (Hilton, 1989) and content validity (Northouse, 1981). For the purposes of this study the word 'illness' on the questionnaire, has been changed to 'cancer' to increase the ease with which the questionnaire is understood and filled out. This alteration in wording was carried out following communication with the author. There are no validity data available for this change in wording.

2. Fear of Relapse/Recurrence Scale (Greenberg *et al.*, 1997)

This five-item scale devised by Kornblith, using a population of adult leukaemia survivors, has also been shown to have both high reliability (Cronbach's alpha = 0.73) and validity (Greenberg *et al.*, 1997; Hill *et al.*, 1998).

3. Fear of Progression Questionnaire (FOP-Q) (Herschbach *et al.*, 2000)

This is a 43-item scale that contains five subscales, affective reactions, partner/family, occupation, loss of autonomy and coping. A Fear of Progression total score can be calculated by adding the scores of the affective reactions, partner/family, occupation and loss of autonomy subscales. Reliability scores for each subscale and the total score were high, with Cronbach's alpha coefficients as follows, affective reactions alpha = 0.92, partner/family alpha = 0.80, occupation alpha = 0.92, loss of autonomy alpha = 0.87, coping alpha = 0.70 and total score alpha = 0.95. There is little evidence of validity except that the scale does not correlate with measures of anxiety. The scale is not currently available in English, therefore, as part of this study it was translated and steps taken to determine its reliability and validity.

The procedure for translation of the questionnaire was as follows. The questionnaire was first translated into English by a native English speaker who was fluent in German. The English translation was then translated back into German by a native German speaker who was fluent in English. A third translator was then involved to remove any discrepancies that were found. Unfortunately, although all the translators were clinical psychologists, none of them worked in the oncology field. The questionnaire was therefore reviewed by three experts in the field. Following this, a pilot study involving five cancer patients was carried out to determine whether the questionnaire was easily understandable to its target group. This procedure was based on questionnaire translation guidelines set out by Bradley (1994).

Sense of Coherence

1. Sense of Coherence Scale (SOC-S) (Antonovsky, 1987)

This scale consists of 29 items measured on a seven-point scale with two anchoring phrases for each item. Measures of reliability indicate good internal consistency (Cronbach's alpha scores from 0.82 to 0.95), good test-retest reliability ($r=0.54$ over a two year period) and validity (Antonovsky, 1993; Flannery *et al.*, 1994). This scale is limited as it does not measure all the domains described by Antonovsky in his model (Antonovsky, 1979). It is, however, the only scale currently available to measure this construct and provides an estimate of an individual's sense of coherence.

Procedure

Participants were recruited from patients attending out-patient follow-up clinics in haematology departments in three general hospitals in the West of Scotland. Doctors involved in the clinics were asked to identify patients who had undergone treatment for first episode, adult Hodgkin's lymphoma, non-Hodgkin's lymphoma or acute leukaemia, who had completed treatment and were in complete remission at time of recruitment. Those who had rapidly deteriorating physical health, acute confusional state or dementia were excluded from the study.

Once identified these patients were approached by the author who explained the purpose and procedure of the study and then gained their consent. Demographic and treatment histories were taken. Participants were given the option to complete the questionnaires in the clinic or to take them home to complete before returning them by post. The participants were instructed to answer the questionnaires with reference to their

experiences of cancer and not to make reference to previous psychological disorder, other chronic illness experiences or previous trauma.

If any of the scores on the PCL-C or IES-R were above threshold for the possibility of the presence of a clinically significant psychological disorder then the appropriate Consultant was notified and recommendations for management were made. This was outlined to patients at the recruitment stage and was also contained in the information sheet.

RESULTS

Demographic data

The ratio of male to female participants was approximately 50:50 which allows the generalisation of the results across gender. Over two-thirds of the sample were either married or lived with a long-term partner suggesting they had good social support. Approximately one fifth of the sample had experienced previous traumatic experiences, such as witnessing a fatal road traffic accident or the death of a loved one. Approximately a quarter had suffered previous psychological disorders such as anxiety or depressive illness. About one third had a chronic illness prior to their cancer diagnosis. These included illnesses such as diabetes, heart disease and Sjogrens syndrome.

Insert Table 1 about here

Descriptive statistics for all variables included in the study are displayed in Table 2. The results of this study show that 3% of the participants scored the minimum score on the fear of progression measure. As can be seen when the mean scores are compared with the minimum possible scores, many of the participants did not score highly on the fear of recurrence measures. Fourteen percent of this sample met DSM-IV diagnostic criteria (APA, 1994) for current PTSD. This was derived by considering a score of 3 or more on the PCL-C as a symptom and following the DSM-IV diagnostic criteria (Weathers *et al.*, 1993). As can be seen from Table 2 many of the participants were also experiencing varying levels of PTSS, as indicated by the mean scores on the PCL-C.

Insert Table 2 about here

Reliability and validity of the translated Fear of Progression Questionnaire

Reliability and validity statistics were carried out on the Fear of Progression Questionnaire. Cronbachs alpha coefficients and item-total correlation scores are displayed in Table 3.

Insert Table 3 about here

The Cronbach's alpha coefficients of all the subscales, except the coping subscale, indicate good reliability, with all scores being greater than 0.7. This result is supported by the item-

total correlations, which based on item-total correlation coefficients of greater than 0.2 (Streiner and Norman, 1989), show that all items in these subscales add to the homogeneity and reliability of the scale. However the reliability of the coping subscale is poor and only four of the nine items have item-total correlation greater than 0.2. This suggests that this subscale has poor reliability based on both Cronbach's alpha and the item-total correlation scores. The validity of the Fear of Progression questionnaire was determined by correlating it with the Fear of Recurrence questionnaire (Northouse, 1981) and the Fear of Relapse scale (Greenberg *et al.*, 1997). Correlations among the scores on these three measures were high; fear of progression with fear of recurrence, $r = 0.728$, $p < 0.01$; fear of progression with fear of relapse, $r = 0.740$, $p < 0.01$. This indicates that the fear of progression questionnaire has good convergent validity.

Examination of hypotheses

In order to determine the relationship between PTSS and the two independent variables, sense of coherence and fear of recurrence, a simultaneous multiple regression was performed. The Fear of Progression total score was used in this analysis as it had the highest reliability of the three fear of recurrence measures. Table 4 displays the results of this analysis.

 Insert Table 4 about here

As can be seen from Table 4 the regression was a good fit (Adjusted $R^2 = 72\%$) and the overall relationship was statistically significant ($F(2, 25) = 35.391$, $p < 0.01$). Fear of recurrence was positively related to PTSS and sense of coherence was negatively related to

PTSS. Both showed a statistically significant relationship with PTSS as indicated by the *t* values. The association of fear of progression to PTSS appears stronger than that of sense of coherence to PTSS as indicated by fear of recurrences' larger beta weight.

A simple linear regression was carried out between sense of coherence and fear of recurrence. The results of this analysis can be seen in Table 5.

 Insert Table 5 about here

As can be seen from Table 5 the regression was a reasonable fit (Adjusted $R^2 = 31\%$) and the overall relationship was statistically significant ($F(1, 29) = 14.53, p < 0.001$). Sense of coherence was negatively related to fear of recurrence, suggesting that as sense of coherence increases, so fear of recurrence decreases.

DISCUSSION

Few studies to date have attempted to link PTSD in cancer patients with theoretical models of PTSD. This study set out to examine links between fear of cancer recurrence and Ehlers and Clark's model of PTSD (Ehlers and Clark, 2000). The results support the hypothesis that those with a high fear of recurrence also have higher PTSS than those with lower levels of fear of recurrence. This supports the suggestion that an individual's fear of recurrence may be perceived as a 'sense of serious current threat', thus affecting their appraisals and memory of the trauma and increasing the possibility of them experiencing

PTSS. This may give us some indication of why, in spite of the different nature of cancer from other potential traumas, PTSD occurs in cancer patients.

The study also hypothesised that sense of coherence would have a role in mediating and moderating levels of fear of recurrence and PTSS. The results support these hypotheses, showing statistically significant relationships between a high sense of coherence and lower levels of fear of recurrence and PTSS. Sense of coherence may play a role in mediating and moderating an individual's appraisal of their trauma. This is consistent with previous studies that have shown sense of coherence is a significant direct predictor of psychological stress (Mullen *et al.*, 1993) and is related to well-being in cancer patients (Forsberg *et al.*, 1996). Since sense of coherence is proposed to be a stable construct (Antonovsky, 1979), it is possible that the sense of coherence scale could be used as a screening measure to highlight individuals, newly diagnosed with cancer, who may be vulnerable to PTSS. Future research would need to confirm the stability of sense of coherence, before carrying out a longitudinal study looking at its relationship to PTSS.

A secondary aim of the study was to translate and standardise the fear of progression questionnaire (Herschbach *et al.*, 2000). As can be seen from the results the four anxiety subscales and the overall total score show good reliability and validity. However, the coping subscale showed poor reliability and no measure of validity was possible within the context of this study. This study provides preliminary data on the reliability and validity of this questionnaire, but further research is required before firm conclusions can be made. Due to the participant numbers it was not possible to carry out a principal components analysis on the questionnaire. Although this has already been carried out with the German version of the questionnaire it is necessary to revalidate the English version of the

questionnaire (Steiner and Pearlstein, 2000). Further investigation of the coping subscale of the questionnaire is also required due to its poor reliability. This may have been due to a loss of meaning during the translation process or a result of the low numbers in the study. This particular subscale should be reviewed before it could be considered for use in future research.

Previous authors have suggested that “fear of cancer recurrence is almost universally present” p.271 (O’Neill, 1975). The results suggest that some of the participants have low to moderate levels of fear of recurrence. This is consistent with previous research (Vickberg, 2001). However, neither this study nor Vickberg’s (2001) study have tried to determine what level of fear of recurrence is clinically significant. Standardisation of measures of fear of recurrence on British populations is a critical area of future research if more accurate prevalence data are to be collected and the psychosocial impact of fear of recurrence is to be determined.

Participants’ who had previous traumatic history, previous psychological disorder or who suffered from another chronic illness were included in this study. These factors may make the individual vulnerable to developing PTSD (MacFarlane, 1989) and those who had previous trauma history may have been suffering from PTSD prior to the diagnosis and treatment of their cancer. The participants were therefore requested to answer the questionnaires with reference to their cancer experience and not with reference to any previous experiences. Although this instruction will have reduced the effect these variables may have had on the results, the results must be interpreted with this limitation in mind given that approximately 50% of the sample population fell into at least one of groups described above.

When proposing a model that hypothesises links between three variables and has more than one dependent variable, structured equation modelling is the most appropriate analysis. It allows the inclusion of more than one dependent variable which allows relationships to be determined taking account of all other relationships in the model. This analysis requires a robust theory and large sample sizes and therefore was not possible with these data. As preliminary support has been found for the theory, it would be beneficial to carry out further research with greater participant numbers to allow the use of structural equation modelling to investigate the relationships in this model further. This would also allow the examination of the differential contributions of fear of recurrence and sense of coherence to the variance of PTSS severity which has not been possible in the context of this study. If future research supports the model proposed, this will have implications for the focus of treatment of PTSS in cancer patients. In particular it will allow determination of appropriate approaches to treatment of PTSD in this population.

This study represents an initial step toward understanding the mediators and moderators of PTSS and to linking general theoretical models of PTSD with PTSS in haematological cancer patients. Further studies are required to replicate and extend the research in this area.

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Table 1: Sample Characteristics

Characteristic	Descriptive Statistic
Gender	
Female	n=16
Male	n=19
Age (mean/range)	51 yearsold/22-80 years old (16.23sd)
Marital Status	
Married or have a main partner	n=27
Single	n=8
Time since diagnosis (mean/range)	27 months/ 7-84 months (23.03 sd)
Time since treatment completion (mean/range)	20 months/ 3-72 months (21.39 sd)
Diagnosis	
Non-Hodgkin's	n=18
Hodgkin's	n=5
Leukaemia	n=12
Chemotherapy	
Yes	n=35
Radiotherapy	
Yes	n=15
No	n=20
Bone Marrow Transplant	
Yes	n=7
No	n=28
Previous traumatic experience	
Yes	n=7
No	n=28
Previous psychological disorder	
Yes	n=8
No	n=27
Previous chronic illness	
Yes	n=10
No	n=25

Table 2: Descriptive statistics for all variables included in analysis.

	Possible Range	Sample Range	Mean (Standard Deviation)
Fear of progression scale – Affective reactions	13-65	13-56	28.48 (8.16)
Fear of progression scale – Partnership/family	7-35	7-27	13.77 (5.51)
Fear of progression scale – Occupation	7-35	7-32	13.51 (7.18)
Fear of progression scale – Loss of autonomy	7-35	7-27	12.94 (5.98)
Fear of progression scale – Coping	9-45	25-40	31.79 (4.10)
Fear of progression scale – Total score	34-170	34-137	69.00 (22.96)
Fear of recurrence questionnaire – Northouse	22-110	34-92	67.66 (13.29)
Fear of recurrence questionnaire – Kornblith	5-25	6-22	11.94 (3.63)
PCL-C	17-85	18-64	28.16 (11.50)
IES-R – Intrusion	0-32	0-24	5.00 (6.88)
IES-R – Avoidance	0-32	0-25	5.03 (7.32)
IES-R – Hyperarousal	0-24	0-21	3.73 (5.54)
SOC Scale	29-203	104-183	148.06 (20.23)

Table 3: Reliability data for Translated Fear of Progression Questionnaire subscales and total score.

	Cronbachs alpha coefficient	Item-total correlation: Range of scores
Affective reactions	0.84	0.24-0.59
Partnership/family	0.77	0.22-0.69
Occupation	0.92	0.56-0.91
Loss of autonomy	0.90	0.59-0.86
Coping	0.44	-0.03-0.44
Total score	0.94	0.07-0.75

Table 4: Regression analysis for variables predicting posttraumatic stress symptomatology.

	B	Standard Error B	β	t
Fear of Progression	0.238	0.056	0.562	4.247*
Sense of Coherence	-0.183	0.063	-0.385	2.913*
F (2, 25)	35.391, p<0.001			
Adjusted R ²	0.718			

*p<0.01

Table 5: Regression analysis for variable predicting fear of recurrence.

	B	Standard Error B	β	t
Sense of coherence	-0.665	0.174	-0.578	3.81*
F (1, 29)	14.53,			
Adjusted R ²	p<0.001	0.311		

*p<0.001

CHAPTER 5

SINGLE SUBJECT RESEARCH STUDY

A Comparison of Guided Imagery, Attention to and Distraction From Pain in the Management of Chronic Pain: A Single Case Study.

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Prepared in accordance with the guideline for submission to *Behaviour Research and Therapy* (Appendix A)

ABSTRACT

Cognitive coping strategies such as attention to and distraction from pain have been shown to have a positive effect on pain (Fernandez & Turk, 1989). The present study uses a single case design to investigate the effectiveness of four cognitive coping strategies; *imagery distraction*, *non-imagery distraction*, *imagery attention* and *non-imagery attention*, on reported pain sensation in a chronic back pain patient. Given that previous studies suggest that attentional strategies are more effective than distractional strategies for chronic pain (Cioffi, 1991; McCaul & Haugtvedt, 1982) and that imagery techniques have been shown to be effective in clinical populations (Fors & Gotestam, 2000; Syrjala, Donaldson, Davis, Kippes, & Carr, 1995), it was hypothesised that the imagery strategies would be more effective than the non-imagery strategies and that the attentional strategies would be more effective than the distractional strategies in reducing reported pain sensation. The *imagery distraction* task was found to be the most effective strategy for reducing reported pain sensation, providing support for the first hypothesis but not the second. The author suggests that the *imagery distraction* task may have been more successful than the *imagery attention* task due to the length of intervention being too short. Neither of the non-imagery tasks produced a reduction in reported pain sensation.

Keywords: chronic pain, attention, distraction, guided imagery