

## **CHAPTER 12**

### **12.0 PHASE 2 - A PILOT STUDY**

#### **1.2.1 Introduction**

Phase 2 is a pilot study with an attempt to work out a treatment model which would deal with the non-compliance by helping the patient to more readily accept treatment and its follow up. A therapeutic intervention model was developed, which would attempt to strengthen self-esteem, deal with fears of cancer and try to reverse some cognitive distortions. This was based on some of the literature and research on combatting non-compliance, together with cognitive therapy principles and treatments such as relaxation therapy. The model was scheduled to cover seven sessions.

This intervention programme was started with patients who presented with the non-compliant protocol on the predictive model. It soon became apparent, however, that this was not effective. Firstly, many of the patients were also non-compliant to these sessions and dropped out after the first two or three. Unfortunately even those who attended more sessions continued to non-comply with their cancer treatment and did not survive. It is clear that the very same traits which lead to non-compliance with oncology treatment now lead to non-compliance with the psychotherapy programme. A break through occurred following a chance meeting with a non-compliant patient as presented in the following anecdote:

One patient, a young man suffering from testicular cancer, attended all the sessions and cooperated with the intervention in every way. His prognosis was excellent as long as he attended all his cancer treatment, be attentive to self care and adhere to follow up sessions.

Some months after he had attended the sessions he was met by accident outside the hospital environment and admitted that he had missed his oncology follow up session several weeks ago because he was 'feeling much better'. He did not seem to intend following this up unless he would feel ill in some way.

He agreed to come for one more psycho-oncology intervention session and the format of the session was very much left to the patient who was simply encouraged to talk especially about the history of his illness. It was soon obvious that the session was following a trauma debriefing protocol, which was emerging in a spontaneous and natural way. It also became obvious that this was something that was potentially extremely effective and that the patient was finding a great deal of meaning and comfort in doing this.

He described how he had realised that his testicle was beginning to swell, how it became larger and larger until his walking became affected. He felt he could not go to anyone because he was shy and embarrassed, and wondered if he had done anything to cause it. Eventually he could only walk with extreme difficulty and he, for the first time, confided in his father, who immediately sent him to hospital. He was too embarrassed to go into the Casualty Department (Emergency Room) and found a health worker in the 'Blood Room' who looked sympathetic

and he showed him his testicle. He was seen by several doctors and admitted for immediate surgery.

The aspect of the surgery that he had found particularly traumatic was the fact that it was done with a spinal block or epidural. The patient was awake with a sheet blocking him from seeing the actual operation. He could not feel pain but was very aware of sensation and movement. He had been extremely traumatised by everything that had happened to him and was suffering from post-traumatic stress.

This trauma debriefing session prompted the more intensive study of post-traumatic stress in cancer patients and in medical conditions in general. It became clear that any psychotherapeutic model addressing non-compliant behaviour would need to address any trauma associated with the medical diagnosis and the treatment itself, if it is to be effective.

Shemesh et. al. (2000) refer to a somewhat similar situation in relating to non compliance in paediatrics: "At present effective treatment techniques (for non compliance) are not always beneficial or applicable" (Shemesh et. al., 2000, p.1). They also point out that current treatments of non-adherence do not focus on the trauma associated with the medical treatment itself, and they suggest that addressing this factor in treatment may prove beneficial.

In view of Shemesh et. al.'s (2000 and 2001) groundbreaking work on PTSD and non-compliance, and in view of PTSD becoming a recognised factor in severe and life-threatening medical conditions and the fact that there were many similarities in the results of the non-

compliant patients in Phase 1 on the MCMI compared to people suffering from more traditional PTSD, a further review of the relevant literature was found to be appropriate and necessary for Phase 2 of this study. The relevance of including a trauma based psychotherapy model to address non compliance is suggested by the research of Shemesh et. al. (2000 and 2001). Therefore a literature search was conducted targeting the following:

1. The revised definitions of PTSD making room for the concept of Medical Trauma and PTSD
2. PTSD and Medical Conditions
3. PTSD in Cancer
  - 3a. PTSD in Breast Cancer
  - 3b. PTSD in Bone marrow transplant
  - 3c. PTSD in Paediatric Cancer
  - 3d. Incidence of Vicarious Trauma in parents of Children suffering from Cancer
4. The avoidance symptom of PTSD
5. Avoidance in Cancer Patients
6. PTSD and non-compliance
7. Treatment Interventions for PTSD in Cancer
8. Recognised Treatments for PTSD
9. Post Traumatic Growth
10. Treatment to encourage Post Traumatic Growth
11. Trauma Debriefing

12. Trauma Debriefing as a Preventive Intervention for Non-Compliance with medical treatment.

### **12.1.1 The revised definitions of PTSD making room for the concept of Medical Trauma and PTSD**

It was not until 1980 that the term PTSD was officially introduced into the psychiatric classification system. The term PTSD provided a common language which has succeeded in bringing together research in a wide range of fields under one, unifying, theoretical umbrella (Joseph et. al., 1997). Historically, combat, robbery, rape, and serious accidents have been included as traumatogenic stressors. Only recently has life-threatening illness been considered as a traumatogenic stressor by the American Psychiatric Association (Neel, 2000).

The diagnostic criteria for PTSD in the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised (DSMIII-R; American Psychiatric Association, 1987), specifically exclude patients with medical illnesses such as cancer and AIDS from the diagnosis of PTSD. These illnesses were not considered to be unusual enough or to be stressors of enough magnitude to produce the psychological aftermath of a traumatic experience. In retrospect this may have contributed to an under recognition in research of the role medical trauma related experiences contributed to non-compliance. The diagnostic criteria for PTSD in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV; American Psychiatric Association, 1994), however, reflect a shift in emphasis from the event itself to the

psychological experience of the person who takes part in the event (e.g., being diagnosed with or surviving cancer). People with histories of cancer could now be considered to be at risk for PTSD.

"PTSD was initially characterized as an anxiety disorder that developed in response to a severe trauma in which an individual experienced, witnessed, or was confronted by actual or threatened death, injury, or loss of physical integrity of self or others. DSM-IV stipulated for the first time, that being "diagnosed with a life-threatening illness" or "learning that one's child" had such an illness was a qualifying stressful event.

These events elicit responses of intense fear, helplessness, or horror and trigger three clusters of PTSD symptoms: re-experience of the trauma (nightmares, flashbacks, and intrusive thoughts), persistent avoidance of reminders of the trauma (avoidance of situations, numbing of general responsiveness, and restricted range of affect), and persistent increased arousal (sleep difficulties, hypervigilance, and irritability). Other common emotional responses associated with such traumas are despair, guilt over actions taken or avoided, and consuming loss. Once established, PTSD symptoms are maintained through instrumental learning. That is, avoidant responses are reinforced because avoidance of the stimuli prevents unpleasant feelings and thoughts." (Cancernet Home Page, 2001)

Cancernet (2001), a website which is directed by scholarly and experienced professionals at the forefront of the field of psycho oncology, point out that the definition in the Diagnostic and Statistical Manual of Mental Disorder, 4th edition (DSM-IV; American psychiatric

Association, 1994) indicates that while PTSD symptoms usually begin within the first 3 months after trauma, there may be a delay of months or even years before symptoms appear.

It is important at this stage to look at some of the diagnostic criteria for PTSD in the DSM-IV (American Psychiatric Association, 1994) as this will highlight the link between the symptoms and behaviours such as avoidance which would have a direct effect on compliance. It will also make clear how cancer patients could potentially meet many of these criteria.

Diagnostic Criteria for 309.81 Post-traumatic Stress Disorder DSM1V (American Psychiatric Association, 1994).

a) The person has been exposed to a traumatic event in which both of the following were present:-

1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.

2) the person's response involved intense fear, helplessness, or horror. Note: In children, this may be expressed instead by disorganised or agitated behaviour.

The above two would most certainly be experienced by cancer patients as those suffering from life threatening disease.

b) The traumatic event is persistently re-experienced in one (or more) of the following ways:-

1) recurrent and intrusive distressing recollections of the event, including images, thoughts or perceptions. Note: In young children, repetitive play may occur in which themes or aspects of the trauma are expressed. In this instance, it would be the doctors, allied medical professionals and recollection of painful or embarrassing procedures or treatments;

2) recurrent distressing dreams of the event. Note: In children, there may be frightening dreams without recognisable content. These may surround the hospital;

(These would most certainly be experienced by cancer patients or patients suffering from life threatening disease).

3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated. (Note: In young children, trauma-specific re-enactions may occur);

4) intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event; and

5) physiological reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event, such as a follow up visit to the Hospital or clinic.

The avoidance group of symptoms would cause the cancer patient to avoid follow up visits or even the treatment itself. Hospitals, nurses and doctors would be painful memories and encounters with the situation.

c) Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:-

- 1) efforts to avoid thoughts, feelings, or conversations associated with the trauma;
- 2) efforts to avoid activities, places or people that arouse recollections of the trauma;
- 3) inability to recall an important aspect of the trauma. (This was recorded by Kesslels (2003) in his article on how little patients remember advice from their doctors);
- 4) markedly diminished interest or participation in significant activities;
- 5) feeling of detachment or estrangement from others;
- 6) restricted range of affect (e.g. unable to have loving feelings); and
- 7) sense of a foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span), often, in this instance, a reality.

d) Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:-

1) difficulty falling or staying asleep;

2) irritability or outburst of anger;

3) difficulty concentrating;

4) hypervigilance; and

5) exaggerated startle response.

e) Duration of the disturbance (symptoms in Criteria B,C, and D) is more than 1 month.

f) The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

In summary it is clear that patients traumatised through a diagnosis and treatment of cancer can quite conceivably develop non compliant behaviours in an effort to avoid anxiety provoking stimuli. These need to be identified and addressed in trauma counselling in an attempt to address non-compliant behaviour.

### **12 .1.2. Post Traumatic Stress Disorder (PTSD) and Medical Conditions**

During the past few years the question has been raised of PTSD in medical conditions and much of the research and literature has been with PTSD in cancer patients.

In listing the breakdown of the category at its outline it is more obvious as to the link between distress the cancer patients are feeling, especially the non-compliant ones, and PTSD.

Having established the fact that medical conditions of a potentially life threatening or serious nature (or even perceived to be life threatening to the patient) it is likely that besides the length of the cancer illness traumatizing and re-traumatizing the patient, there have possibly been previous medically traumatic experiences which can be built on by the patient. As has been found in some of the literature that will be quoted, the patient could also have been traumatized by circumstances unrelated to medicine, and be suffering from PTSD from a past experience. In this way the patient might be already avoidant of unpleasant or painful stimuli before they even begin their cancer treatment.

Silver and Cohen's (2001) findings suggest that experience with previous stressors affect an individual's reactions to cancer. Similarly, Baider, Peretz, Hadani, Perry, Avramor and De Nour (2000) who examined cancer patients who were second-generation Holocaust survivors in an attempt to determine whether they react to their illness with the high distress found to be a characteristic of Holocaust survivors. It was concluded that second-generation Holocaust survivors are particularly vulnerable to psychological distress and, when faced with a trauma

such as breast cancer, react with extreme psychological distress. Re-traumatizing on existing trauma may compound it.

Dougall, Herbeman, Delahanty, Inslicht and Baum (2000) examined the cumulative effects of trauma in 108 workers at the site of a major air disaster at 4 time points over a year following the crash. Accumulation of a variety of different traumatic experiences appeared to sensitize workers to the new stressor and to perpetuate chronic stress. They feel that understanding the role of trauma history is important for improving intervention efforts aimed at alleviating stress following a trauma, a fact that would be important in the ongoing illness and treatment of cancer.

Yehuda, Kahana, Schmeidler and Southwick (1995) examined the relationships among cumulative lifetime trauma, recent stress, and the presence and severity of current posttraumatic stress disorder (PTSD) symptoms in 72 non-treatment seeking Holocaust survivors. The 40 subjects found to have PTSD reported greater cumulative trauma and recent stress than those 32 subjects without PTSD. They found that the severity of PTSD symptoms, cumulative trauma, and recent stress were significantly associated.

Traumatizing and re-traumatizing an existing trauma may compound it. This also brings up the question of preventing medical trauma unrelated to the cancer e.g. childhood asthma or operations.

An interesting study which examined cognitive distortions in PTSD with important implications for non compliance as that of Muran and Motta (1993) who studied cognitive distortions and irrational beliefs in post-traumatic stress, anxiety, and depressive disorders. Only the clinical group endorsed more dysfunctional cognitions than did the non-clinical group, which supports the uniqueness of the PTSD group as differing cognitively from clinical groups.

Another important aspect which could apply to cancer patients is from Allen, Coyne and Huntoon (1998) and Herman's (1992) formulation of complex posttraumatic stress disorder (PTSD). This was not incorporated into the Mental Disorders-IV (DSM-IV; American Psychiatric Association, 1994), but finds ample confirmation in personality assessment of women in inpatient treatment for trauma-related disorders. The PTSD is compounded by several traumatic factors where traumatization and re-traumatization occurs, becoming a difficult treatment problem.

Relevant to this, Du Hamel, Ostroff, Bovbjerg, Pfeffer, Papadopoulos and Redd (2000) discuss the oncology treatment setting, where the possibility of re-traumatization is a patient concern.

Tedstone and Tarrier (2003) mention that PTSD has been described in myocardial infarction, cardiac surgery, haemorrhage and stroke childbirth and miscarriage, abortion, gynaecological procedures, HIV infection, awareness under anaesthesia etc. Generally the severity of the illness itself is not predictive of PTSD. However the onset of some physical illness, for

example, myocardial infarction, (MI) stroke or haemorrhage may be sudden, unexpected, and immediately life threatening and as such appear to be comparable to the general PTSD literature. They found that, "the presence of PTSD most probably influences the patients' use of health care resources and clinical outcomes" (Tedstone and Tarrier, 2003, p. 410). This avoidance response would definitely be related to non-compliance in a medical context.

Jones, Griffiths, Humphris, Skirrow (2001), examined prospectively the relationship between memories of intensive care (ICU) and levels of anxiety after ICU discharge, the stability of these memories with time, and their relationship to the development of acute post-traumatic stress disorder (PTSD)-related symptoms. They concluded that the development of acute PTSD-related symptoms might be related more to recall of delusions (delusional memories during the illness) alone. This study suggests that even relatively unpleasant memories for real events during critical illness may give some protection from anxiety and the later development of PTSD-related symptoms when memories of delusions are prominent.

Stoll, Kapfhammer, Rothenh Añusler, Haller, Briegel, Schmidt, Krauseneck, Durst, and Schelling, (1999) pointed out that many survivors of critical illness and intensive care unit (ICU) treatment have traumatic memories such as nightmares, panic or pain which can be associated with the development of PTSD. They studied long-term survivors of the acute respiratory distress syndrome (ARDS) working with a questionnaire which was found to be a responsive, valid and reliable instrument to screen survivors of intensive care for PTSD.

### 12.1.3 PTSD in cancer

It is the argument of the current thesis that traumatic stress can also undermine treatment compliance even in cancer patients with a good prognosis. Identification of posttraumatic stress disorder (PTSD) symptoms and diagnoses in survivors of cancer is a growing area of research (Cordova, Cunningham, Carlson and Andrykowski, 2000).

The stressor criterion for PTSD which has been recently modified to include life-threatening illnesses, such as cancer, as precipitating traumatic events leading the way for research to elucidate the impact of the threatening diagnosis on psychological adaptation and treatment compliance (Smith, Redd, Du Hamel, Vickberg and Ricketts, 1999a; Schmitt 2000).

"While warfare, physical assault, and serious accidents seem clear-cut in their abilities to engender posttraumatic distress, a relatively new stressor under scrutiny is that of life-threatening illness. More specifically, it may be argued that the physical disease of cancer possesses traumatogenic properties" (Neel, 2000, p. 85).

Ronson and Razavi (2000) point out that cancer and its treatments constitute an almost continual source of physical and psychosocial stress, and place a constant demand upon patients' adaptive resources and coping strategies. They feel that the impact of these resources on patient's treatment compliance requires further understanding and study.

"Over the past several years, our ability to treat patients with cancer has increased steadily.

As a result of this progress, a greater percentage of these patients is surviving. Also, specific psychological symptoms related to the cancer experience, such as re-experience, avoidance, and heightened arousal, which are typical of post-traumatic stress disorder (PTSD), have also been reported. By definition, PTSD is a syndrome that has a major impact on functioning.

The intrusiveness, physiologic arousal, and avoidance phenomena are a cluster of symptoms that can severely limit an individuals' ability to function adequately." (Redd, Du Hamel, Vickberg, Ostroff, Smith, Jacobsen and Manne, 2001, p. 137)

It is possible that non-compliance in oncology treatment may be linked with avoidant sequelae of possible PTSD features in patients. Mehnert, Meuller and Koch (2003) also write about ASD, Acute Stress Disorder in cancer.

It must be noted at this point that although there is a great deal of overlapping and similarity between the PTSD patient's profile and the non-compliant patient's profile on the MCMI-11, this is in no way conclusively established. However, due to the fact that PTSD is emerging as a strong factor in non-compliance, and the study links through the MCMI-11, there is sufficient reason to do a pilot study of a trauma debriefing intervention for Phase 2.

It is the argument of the current thesis that traumatic stress can also undermine treatment compliance, and that a trauma debriefing intervention could reduce non-compliance in oncology patients with a good prognosis.

White and Black (2003) consider a cognitive model of PTSD by examining the relationship between sense of coherence and fear of recurrence to post traumatic stress symptomatology, in haematological cancer survivors. Their results were statistically significant and they suggest that the construct can be used as a screening measure for potentiality for PTSD in cancer survivors.

Hampton and Frombach (2000) investigated gender differences in the prevalence and predictors of posttraumatic stress disorder (PTSD) in a sample of cancer patients. PTSD symptoms were more frequently reported by women (27% vs 10%). Predictors of PTSD for women were: (1) perceived intensity of cancer treatment; (2) problems with health care professionals; and (3) cognitive avoidant coping style. For men, the sole predictor of elevated PTSD scores was behavioural avoidance. The role of avoidant coping style and behavioural avoidance in treatment compliance requires further scrutiny.

Baum and Posluszny (2001) propose that serious illnesses like cancer are complex stressors composed of several interrelated stressors triggered by the identification of the disease. A cancer diagnosis is a psychological stressor that can produce cognitive and emotional crises and persistent distress. It also indicates that this turmoil and stress create a broader context in which stressors associated with surgery, chemotherapy, and other upsetting aspects of having cancer treatment are experienced. The sudden life peril introduced by such a diagnosis and the considerable fear most people experience when they think about having cancer set the stage for catastrophic thoughts or other reactions to the reality of cancer. These effects of trauma associated with diagnosis seem to persist as the particular stressors associated with

treatment are superimposed on them. The authors suggest that traumatic stress can undermine adjustment to cancer treatment, quality of life, and survival and should be a target of psychotherapeutic interventions. It is the argument of the current thesis that traumatic stress can also undermine treatment compliance even in good prognostic cancer patients.

#### 12.1.3.1 PTSD in Breast Cancer

Shortly after the DSM-IV (American Psychiatric Association, 1994) was published, Cordova, Andrykowski, Kenand, McGrath, Sloan and Redd (1995) noted that the diagnosis of life-threatening illness now met the diagnostic criteria for traumatic stressor exposure for post-traumatic stress disorder (PTSD). They noted that in survivors of breast cancer, these symptoms might be fairly common, may exceed the base rate of these symptoms in the general population, are associated with reports of poorer quality of life, and, therefore, warrant further research and clinical attention.

Pitman, Lanes, Williston, Guillaume, Metzger, Gehr and Orr (2001) performed psycho-diagnostic, psychometric, and psycho-physiological evaluations on 37 patients referred by local surgeons approximately 2 years after tissue diagnosis of Stage I-III breast cancer. They found significantly elevated physiologic responses during script-driven imagery of personal breast cancer experiences and concluded that their results provided psycho-physiological support for the proposition that being diagnosed with life threatening illness, in this case, breast cancer, can be a stressor sufficient to result in PTSD.

Naidich (1997) found that women diagnosed with breast cancer displayed unequivocal symptoms of PTSD, including intrusive thought and avoidance behaviour related to breast cancer stimuli. They also found that the presence of PTSD symptomatology in women with breast cancer was significantly related to a lack of knowledge regarding important diagnostic information. Additionally, women with breast cancer exhibited significantly higher levels of depression than women in a comparison group. She also notes that medical treatment necessitates repeated exposure to potentially traumatic stimuli.

Similarly, Naidich and Motta (2002) showed that breast cancer patients displayed unequivocal symptoms of PTSD, including intrusive cognition and avoidance behaviour related to breast cancer stimuli.

Khalid and Gul's (2000) study investigated the presence of PTSD-like symptoms in women diagnosed with breast cancer who had undergone mastectomy. They found that the women who were unmarried and received more extensive and aggressive type of cytotoxic treatment were more likely to experience PTSD-like symptoms. This suggests that a lack of social or emotional support systems places such individuals at further risk for PTSD. They also found that stage of the disease and quality of life were predictors of PTSD-like symptoms in women after mastectomy.

Andrykowski, Cardova, McGrath, Sloan and Kenooy (2000) found that in general, PTSD symptoms in patients treated for cancer did not diminish over time. What they regarded as most significant, was that the research suggested that women with greater PTSD symptoms at

the initial interview were less likely to participate in the follow-up interview. This relates directly to non-compliance in the cancer patient being the result of PTSD. The person becomes so traumatized that avoidance heightens and the patients avoid the treatment centre.

Roper (2000) assessed the incidence of PTSD in women with Stage II-IV breast cancer following high-dose chemotherapy and autologous haematopoietic progenitor stem cell support. The results indicated that 6% to 11% of the sample would be likely to meet DSM-IV (American Psychiatric Association, 1994) criteria for PTSD. However, overall, numerous participants reported experiencing some PTSD symptoms. Almost 13% of participants met the criteria for the re-experiencing symptoms, 38% met criteria for the avoidance/numbing symptom cluster, and 39% met criteria for the arousal symptom cluster. Elevated depression and anxiety symptoms were related to increased levels of PTSD symptoms.

Yurek, Farrar and Andersen (2000) found that significantly higher levels of traumatic stress and situational distress regarding the breast changes were reported by the women receiving a modified radical mastectomy (MRM) with breast reconstruction in contrast to the women treated with breast-conserving therapy (BCT), a result which is to be expected.

Tjemsland, Soreide and Malt (1996a) in their study found that the level of acute posttraumatic stress response to breast cancer surgery seemed best predicted by pre-morbid variables relating to stress.

Tjemsland, Soreide and Malt (1996b), however, in another report found that previous physical and psychiatric health parameters showed no association to acute traumatic stress symptoms except for those who had experienced a "serious illness/accident/hospitalisation last year" who had some more avoidant symptomatology, which possibly related to traumatizing and re-traumatizing. Avoidance would, obviously, lead to non-compliance.

Baider and De-Nour (1997) examined the relationship between psychological distress and the cognitive styles characteristic of post-traumatic stress disorder (PTSD) (i.e. intrusion and avoidance) in 283 female breast cancer patients. In these patients a very strong relationship was found between intrusion and psychological distress, but only minimal links between avoidance and psychological distress were found.

Eckhardt (1999) examined the relationships between individual symptom clusters of PTSD and "fighting spirit", "anxious preoccupation", and "avoidance coping styles" among women with primary breast cancer. Positive relationships between "anxious preoccupation", "coping style" and "re-experiencing" and hyper-arousal symptoms" were observed. "Anxious preoccupation" was positively linked to "avoidance/numbing" PTSD symptoms. Positive correlations between "avoidance coping" and "re-experiencing and hyper-arousal" symptom clusters were found. "Avoidance coping" and "avoidance/numbing" PTSD symptoms were positively associated. Multivariate regression analyses revealed that "anxious preoccupation", "avoidance coping", and age predicted total PTSD. "Anxious preoccupation and age predicted "re-experiencing and hyper-arousal" symptoms while "avoidance coping", "fighting spirit", and not having a child predicted "avoidance/numbing" PTSD symptoms. As expected, cancer

patients' internal hypervigilance scores were significantly higher than their external hypervigilance scores.

#### **12.1.3.2 PTSD in bone marrow transplant**

Smith et. al. (1999) examined the validity of the PTSD symptomatology in 111 adults who had undergone bone marrow transplantation an average of 4.04 years previously. They found that the subjects who met PTSD symptom criteria on the PCL--C had significantly lower physical, role, and social functioning, greater distress and anxiety, and significantly more intrusive and avoidant responses than those who did not meet PTSD symptom criteria.

In a later study, Du Hamel, Smith, Vickberg, Johnson, Papadopoulos, Ostroff, Winkel, Manne and Redd (2001) investigated the association of trauma-related symptomatology and recent life events in 100 cancer survivors following bone marrow transplantation. Their results indicated that the more negative life events a person experienced, the greater his/her trauma-related symptomatology.

Widows, Paul, Jacobsen and Fields (2000) examined whether trauma appraisals, coping, social support, and social constraint were associated with the severity of PTSD symptoms in cancer patients (aged 21 to 70 yrs) who had undergone bone marrow transplantation. Results indicated that 5% of participants met diagnostic criteria for current PTSD. The participants reported an average of three to four symptoms of PTSD.

Mundy, Blanchard, Cirenza, Gargiulo, Maloy and Blanchard (2000) assessed 17 women who had undergone autologous bone marrow transplants for their breast cancer and 20 other women who had been treated for breast cancer (but not with bone marrow transplants) by structured clinical interviews examining each stage of the breast cancer experience. The two groups did not differ on incidence of PTSD, major depressive disorder, or generalized anxiety disorder at any stage. However the authors found a high rate of PTSD over the various stages of the cancer experience, 35% for the combined sample (breast cancer patients with or without bone marrow transplants), with cancer diagnosis being the most likely point for developing PTSD. This is a theme that keeps appearing in the literature, that the foundations for PTSD are laid very early on in the illness.

#### **12.1.3.3 PTSD in paediatric cancer**

Werner (1999) points out that in recent years more and more children are surviving cancer, often due to more intensive treatment protocols. It has been proposed that there are specific risk and resistance factors which mediate how children adjust to a chronic and traumatic illness such as cancer, with its painful and/or distressing treatments.

Barakat, Kazak, Gallagher, Meeske and Stuber (2000) concluded that trauma responses to childhood cancer and its treatment have implications for the long-term adaptation of children and their families. They viewed early signs and symptoms of posttraumatic stress and stressful life experiences as requiring early assessment and intervention.

In the earlier years of research into PTSD in cancer patients, Kazak, Stuber, Barakat and Meeske (1996) note that there are many aspects of serious illness and medical treatment that can be traumatic for patients and families. Appreciation of these experiences has led to consideration of post-traumatic stress as a paradigm for understanding the long-term psychological sequelae of illness, fitting in with a family systems paradigm because the persistent, long-term reactions to illness and treatment contextually impact family members as well as the patient.

In an assessment of 40 long-term paediatric cancer survivors (aged 12 to 35 yrs), it was found the majority of participants met at least partial current PTSD criteria. Erickson and Steiner (2000) and 'Anonymous' and Steiner (1999) point out that years after treatment, the relatively high levels of current PTSD and trauma-associated symptoms reflect the long-term deleterious impact of having cancer as a child. They feel that these survivors demonstrate avoidance and a repressive adaptive style but also admit Somatoform symptoms. They feel that this may be an essential way to detect and treat trauma-related distress in this population.

In a later article, Erickson and Steiner (2001) assessed these constructs with a structured interview for PTSD, a clinical interview, and self-report questionnaires. Thirty five out of 40 participants (88%) currently met at least one trauma symptom at a functionally significant level. Again they mention the high levels of restraint and low levels of distress, representative of a repressive adaptive style.

Werner's (1999) findings indicated that both paediatric cancer patients and their parents experienced minimal to mild post-traumatic stress symptoms, but a small subgroup of children with cancer and their parents did report significant levels of post-traumatic stress symptoms. Of the symptoms related to post-traumatic stress, avoidance behaviours proved to be the most frequently endorsed. There was also evidence of a high degree of reciprocal interaction and influence of post-traumatic stress symptoms between children and their parents.

Davidson, Inslicht and Baum (2000) feel that the dependent nature of children may put them at greater risk for exposure to some traumatic stressors and may exacerbate the impact of other stressors. Some develop posttraumatic stress disorder (PTSD) or other post-stressor syndromes. They felt that of particular concern among young children is the possibility that trauma can have broader, systemic effects, sensitizing them to stressors, altering belief systems and world view, and affecting their sexual and maturational progress in critical development phases.

As previously mentioned, adolescents with cancer, as with other illnesses, have particular problems, due to their developmental life stage. Madan, Brown, Foster, Vega, Byars, Radenberger, Bell and Lambert (2000) examined identity formation among adolescent survivors of childhood cancer. A greater frequency of survivors than their healthy peers was found within the foreclosed identity status, i.e. Factors associated with the foreclosed identity status included the cancer diagnosis, symptoms of PTSD, and family functioning characterized by greater levels of conflict. The authors felt that the foreclosed identity status

may serve a protective function in assisting survivors to cope with the stressors of the cancer experience.

Looking further a field than paediatric cancer, Wintgens, Boileau and Robaey (1997) discuss post-traumatic stress symptoms and treatment in children after diseases such as cancer, organ transplantation, and severe burns. They believe that many aspects of severe childhood diseases are traumatic, as defined by the DSM-IV (American Psychiatric Association, 1994) severe illnesses are life-threatening, medical procedures threaten the child's physical integrity, and disorganized behaviour periods are common. They see the symptoms differing according to the child's developmental stage and type of trauma.

An interesting view is put forward by Van Halem (2003). She feels that medical trauma in even simple medical procedures can be more devastating than those previously seen as traumatogenic, as it affects the basic trust in a child. She points out that small children always comprehend the perceived function of their parents and/or guardians to protect them through their traumatic medical experiences. She suggests that such experiences confuse children and undermine their basic trust in their parental figures. However, non compliance with medical treatment in the case of children, it is more likely to reflect the beliefs or anxieties of the parents).

#### **12.1.3.4 Incidence of vicarious trauma in parents of children suffering from cancer**

It is clear that parents vicariously experiencing their children's cancer are very prone to PTSD and traumatic stress symptomatology.

Darbasie (2000) compared psychological symptoms of anxiety and posttraumatic stress and characteristics of the social support networks of parents of childhood cancer survivors. The manifestation of posttraumatic stress symptoms emphasizes the importance of continuing investigations into the pervasive and long-term effects of the cancer experience.

Best, Streisand, Catania and Kazak (2001) evaluated the association between parental anxiety during treatment for childhood leukaemia and post-traumatic stress symptoms (PTSS) after treatment ends. The authors found anxiety during treatment to be a significant predictor of later PTSS for mothers, but not fathers. Anxiety, self-efficacy, post-traumatic growth and length of time since treatment ended were associated with parental avoidance. The authors found that highly anxious parents are at risk for PTSS and may benefit from approaches that decrease anxiety during treatment and afterwards.

Niles (1996) examined childhood cancer survivors and their parents. Parents of survivors reported higher levels of post-traumatic stress, with 33.3% of fathers and 40.8% of mothers reporting symptoms at the severe level. Survivors reported more post-traumatic symptoms which are avoidant in nature than non-ill children/adolescents, but does not report more total

post-traumatic symptoms or symptoms which address intrusive reminders than a comparison group.

Manne, Du Hamel, Gallelli, Sorgen and Redd (1998) examined posttraumatic stress disorder (PTSD) in 65 mothers (aged 22-54 yrs) of survivors of childhood cancer. As many as 6.2% of the sample were diagnosed with current PTSD. An additional 20% had sub-clinical PTSD. One of 4 mothers with PTSD diagnoses had a co-morbid diagnosis of an anxiety or depressive disorder.

Kazak, Barakat, Meeske and Christakie.(1997) examined psychological sequelae in 130 former childhood leukaemia patients and 155 comparison participants and their parents. The major dependent variables are symptoms of anxiety and post-traumatic stress, family functioning, and social support. Multivariate analyses of covariance indicated significantly more posttraumatic stress symptoms in mothers and fathers of childhood leukaemia survivors. Interestingly, there were no differences between survivors and peers.

Kazak, Stuber, Barakat, Meeske, Guthrie and Meadows (1998), in a later report, found PTSD symptoms in parents of survivors of childhood cancer. They found that for both mothers and fathers, anxiety was the strongest predictor of PTSD symptoms. The current family and individual variables also contributed significantly, particularly with respect to the individual contributions of perceived life threat, perceived treatment intensity, and social support. Objective medical data did not contribute to PTSD symptoms.

Barakat, Kazak, Meadows, Casey, Meeskeand Stuber (1997) found that mothers and fathers of childhood cancer survivors showed significantly higher levels of posttraumatic stress symptoms than comparison parents. However, as Kazak et. al. (1998) found, the survivors themselves did not differ from their healthy counterparts.

Libov (1997) administered structured interviews to forty-nine mothers of paediatric cancer survivors to assess the presence of PTSD symptomatology. Mothers were also administered self-report questionnaires to measure variables which may predict PTSD symptoms as well as overall adjustment. Results indicated that 27% of the mothers met criteria for a diagnosis of lifetime PTSD. Ninety percent of the mothers reported at least one re-experiencing symptom, typically distressing and intrusive recollections (61%), and/or feeling distressed when something reminds them of their child's illness (80%). Only one subject reported a true flashback experience, and few mothers (14%) reported recurrent and distressing dreams. The frequency of each avoidance symptom was consistent, occurring about 30% of the time, with the exception of psychogenic amnesia which was quite rare in this sample (8%).

Hypervigilance was the most common arousal symptom reported (41%), while the exaggerated startle response was reported infrequently (12%). The most significant predictors of PTSD symptomatology were the mothers' current perception of life threat, the number of low magnitude stressors experienced in the past year, and reported income level.

#### **12.1.4 The avoidance symptom of PTSD**

Perhaps the aspect of PTSD most significant to non compliance and often described would be avoidance behaviour and is therefore treated in a special section here.

Huang, Shen, Zhaa and Jiang (2000) studied cancer patients in China. They discuss the patients' use of avoidance as a positive coping style and acceptance-resignation as a negative coping style. In one sense this can be a positive coping style in that the patient is relieved from the immediate stress, however, in the long term the patient could avoid the treatment centre and there avoid treatment and follow up. Ehlers and David (2000) talk of avoidance of reminders of the trauma. Avoidance of the site of the trauma, would in medical trauma, be the medical setting. It is clear that research needs to examine the link between trauma, avoidance defences and possible non-compliance with medical treatment.

Horowitz (1976), Horowitz, Wilner and Alverez (1979) and Joseph (1997) shed a different light upon the role of avoidance. They argue that avoidance is a part of normal adaptation. (i.e. An individual will go through phases of re-experiencing and avoiding thinking about the trauma). Thus the role of avoidance in coping with stress seems ambiguous: first, avoidance impedes emotional processing and maintains anxiety; but second, avoidance may be necessary to protect a traumatised individual from being overwhelmed by emotion and plays a part in normal processing of the event.

It is clear that the concept of avoidance is complex and can implicate different coping responses: behavioural avoidance (i.e. staying away from reminders); cognitive avoidance (i.e. not thinking about the event); and affective avoidance (i.e. blocking an affective response). It is possible that different types of avoidance are associated with different outcomes. Specifically, if emotion is required in processing, it might be that affective avoidance would have the most generalised inhibitory effect and would be associated with the greatest signs of blocked emotional processing and functional impairment. The studies which have shown avoidant strategies to be adaptive have generally used measures of either cognitive or behavioural avoidance rather than affective avoidance. It is suggested that affective avoidance may be predictive of emotional disorder.

Rosberger, Lebel, Jakubovits, Seguin, August, Loiselle and Lisbona (2003) studied distress, risk perception and coping in patients waiting for a breast biopsy. They found that personal risk of positive biopsy finding was overestimated in half of the patients and correlated with greater distress. The use of cognitive -avoidant coping strategies was associated with greater distress.

Bisbey and Bisbey (1998) describe avoidance behaviour. This can either be conscious or unconscious and consists of the traumatised person avoiding "triggers" that might remind him/her of the event. Some of them might be obvious and known to the individual. Others may be a little more subtle, and outside of the consciousness of the patient. They point out that avoidance behaviour as well as being a symptom of trauma, in fact compounds or exacerbates trauma.

Avoidance in PTSD as described in the DSM1V (American Psychiatric Association, 1994) as follows:

"Marked avoidance of stimuli that arouse recollections of the trauma e.g. thoughts, feelings, and conversations, activities, places and people.

"Stimuli associated with the trauma are persistently avoided. The person commonly makes deliberate efforts to avoid thoughts, feelings or conversations about the traumatic event (Criterion C1) and to avoid activities, situations, or people who arouse recollections of it (Criterion C2). This avoidance of reminders may include amnesia for an important aspect of the traumatic event (Criterion 3). Diminished responsiveness to the external world referred to as "psychic numbing" or "emotional anaesthesia", usually begins soon after the traumatic event. The individual may complain of having markedly diminished interest or participation in previously enjoyed activities (Criterion C4), of feeling detached or estranged from other people (Criterion C5), or of having markedly reduced ability to feel emotions (especially those associated with intimacy, tenderness and sexuality) (Criterion C6). The individual may have a sense of a foreshortened future (e.g: not expecting to have a career, marriage, children, or a normal life span) (Criterion C7)." (DSM-IV, 1994, p. 424-425))

In discussing the criterion for PTSD, Neel (2000, p. 88) says: " The individual must also display at least three avoidance and numbing symptoms to satisfy Criterion C, including efforts to avoid thoughts, feelings, or conversations associated with the trauma, efforts to

avoid activities, places, or people that arouse recollections of the trauma; inability to remember an important aspect of the trauma."

It is clear from these criteria that traumatic avoidance behaviours resulting from trauma could result in non compliant behaviours in cancer patients and therefore undermine their treatment and exacerbate their illness.

### **12.1.5 Avoidance in cancer patients**

Because avoidance is so connected to actual non compliance, these particular symptoms of PTSD are highly relevant to this study.

A significant study was done by Manne, Glassman and Du Hamel (2000), the goal of which was to examine the utility of Creamer's (Creamer, Burgess and Pattison 1990) cognitive processing theory of trauma in a sample of individuals undergoing treatment for cancer. Creamer's theory proposes that avoidance is a maladaptive strategy of dealing with intrusive thoughts about a traumatic experience and suggests that avoidance mediates the relation between intrusive thoughts and later psychological distress. Avoidance increases distress because thoughts and memories are not confronted directly and thus are not processed sufficiently.

They found the results of this study to be partially consistent with Creamer's cognitive processing theory. A moderating effect was found for disease stage on associations between

intrusions, avoidance, physical impairment, and distress. However, they found the mediational model to be supported among patients being treated for more advanced stages of cancer but not among individuals being treated for early-stage cancer. Among early-stage patients, intrusion predicted subsequent avoidance and distress, but avoidance did not predict subsequent distress. The principal finding of this study was that, among individuals with stage 3 and 4 cancer, intrusive thoughts were related to higher avoidance and had an indirect effect on the psychological distress through avoidance. They mention that to their knowledge, this finding is the first evidence indicating that the relation between intrusive thoughts and later psychological distress may be mediated by cancer patients' attempts to avoid thinking about or dealing with reminders of the cancer experience.

This could lead to avoidance of hospitals, doctors and follow up programmes and a general reduction in medical compliance. Phobic avoidance of situations or activities that resemble or symbolise the original trauma may interfere with interpersonal relationships and lead to marital conflict, divorce or loss of a job.

Similarly, Manne, Glassman and Du Hamel(2001) examined the utility of Creamer's (e.g. Creamer et. al., 1990) cognitive processing theory of trauma in patients undergoing treatment for cancer. In this research they found that the mediational role for avoidance was supported among patients with advanced stages of cancer but not for patients with early-stage disease. Among patients with early-stage cancer, deterioration in physical impairment was associated with increases in avoidance, and deterioration in physical impairment increased distress. This

could possibly relate to the length of time they had been treated for the disease or because they see themselves as at a later stage.

Primo, Compas, Oppedisane, Howell, Epping and Krag (2000) examined subgroups of patients to determine differences in responses to stress of a diagnosis of breast cancer in terms of the magnitude and patterns of intrusive thoughts and avoidance, demographic factors and disease characteristics. Results revealed that some evidence was found to support the hypothesis that initial patterns featuring high avoidance at diagnosis were related to subsequent intrusive thoughts. High levels of intrusion at diagnosis, regardless of the level of avoidance, predicted the highest levels of symptoms of depression and anxiety. At this stage medical compliance was not assessed, but could well have been a factor.

McCaul, Sandgren, King, O'Donnell, Branstetter and Foreman (1999) examined possible predictors of distress and adjustment to breast cancer diagnosis and treatment. Sixty one 30 to 82 year old women participated soon after they were diagnosed with Stage I or Stage II breast cancer. Measures of coping, distress and other mood states, and quality of life were gathered at diagnosis and again 4 months later. The most consistent predictor of distress and, to a lesser extent, quality of life, was avoidant coping; in addition, women who reported more avoidant coping were more distressed, setting up some kind of vicious cycle.

Cordova et. al. (2001) found that in their cross-sectional study of 70 breast cancer survivors, greater uncertainty, intrusions, and avoidance behaviours were associated with greater depression and less well-being. Avoidance both reduced and increased anxiety.

Stanton, Danoff-Burg, and Huggins (2002) bring out an interesting point that coping through avoidance at the time of diagnosis predicted decreased distress at 3 months but higher fear of cancer recurrence at 1 year. Avoidance-orientated coping has been shown to be a risk factor for poor general adjustment in several studies of individuals with cancer and this suggests that avoidance is an important risk factor for cancer specific maladjustment. Avoidance can be adaptive initially but maladaptive in terms of long term adjustment.

In a similar vein, Tedstone and Tarrier (2003) mention that PTSD has been described in myocardial infarction, cardiac surgery, haemorrhage and stroke childbirth and miscarriage, abortion, gynaecological procedures, HIV infection, awareness under anaesthesia etc. They found avoidance to be the overriding symptom in all these cases.

#### **12.1.6 PTSD and non-compliance**

There have been some studies where previous exposure to trauma (non-medical) has interfered with medical compliance especially with treatment for HIV/AIDS. (Ricart, Cohen, Alfonso, Hoffman, Quiones, Cohen and Indyk, 2002)

Furthermore, O'Cleirigh, Ironson, Antoni, Fletcher, McGuffey, Balbin, Schneiderman and Solomon's (2003) study examined the relationship between emotional expression and processing in depth, past (non-medical) trauma and long-term survival of and relationship to health behaviour of patients living with AIDS. They found that only processing in depth (and

not emotional expression) was related to medication adherence and to psychosocial variables (perceived stress and social support). They point out that their results underscore the importance of therapy on a deeper level (and not just emotional expression) of traumatic experiences for people living with HIV/AIDS.

Several authors have argued that non compliance with risk reduction and medical treatment can be interpreted as self defeating and self destructive behavioural manifestations of PTSD and early childhood trauma (Cohen, Alfonso,; Hoffman, Milau and Carrera, 2001). However this observation pertained to PTSD in the more classical rather than the medical sense such as early childhood physical and sexual abuse. In addition, they mention that because there are no previous reports of an association between early childhood trauma, PTSD and HIV infection, this needs to be further investigated.

Dew, Kormos, Roth, Murali, DiMartini and Griffith (1999) did a significant study, finding that poor medical compliance has been held responsible in for a large proportion of deaths occurring in heart transplants subsequent to initial post operative recovery. They found that PTSD related to the transplant remained directly associated with heightened risk for mortality even after intermediate morbidities were controlled. They found that the key predictor was poor compliance with medication. The results indicated that poor medication compliance during the first year post-transplant increased risk for acute rejection by over four-fold.

In sum, they suggest the following: "We hypothesize that unlike most episodes of depression and other anxiety-related disorders that occur in the post-transplant years, the specific

occurrence of full-blown PTSD related to the transplant experience indicates a distinct failure of the person to come to terms with the experience: a failure to acknowledge and psychologically incorporate one or more aspects of the events surrounding the transplant experience. Indeed, many of the cardinal symptoms that constitute the disorder embody this failure, e.g. an undesired re-experiencing of the events (through "flashback" experiences and nightmares), and an exaggerated desire to avoid thinking about the event or to avoid circumstances that remind one of the events surrounding the transplant. Recipients who do not psychologically incorporate the transplant experience run the risk of damage to their own physical health." (Dew, et. al. ,1999, p. 559)

Shemesh, et. al. (2001) examined the hypothesis that links symptoms of myocardial infarction (MI) and MI-related post-traumatic stress disorder (PTSD) to non-adherence. According to this hypothesis, patients who are traumatized by their medical illness do not take their medications as prescribed. As a part of the avoidance dimension of PTSD, patients who are traumatized may avoid being reminded of the MI by not taking the medication. They followed MI survivors for 6 months to 1 year. They found that PTSD symptoms were significantly associated with non-adherence to medications. They found no other psychiatric symptom dimensions to be independently associated with non-adherence, however.

They concluded that non-adherence to medications predicts adverse outcome during the first year after an acute MI. Non-adherence is associated with PTSD symptoms, which may either be a marker for or a cause of non-adherence. They suggest that treatment of PTSD may prove to be a useful approach for improving adherence.

Shemesh et. al. (2000) had found that symptoms of PTSD were described in survivors of life-threatening diseases, the trauma being the experiences associated with the disease or its treatment. Based on clinical observations, they hypothesised that a significant proportion of paediatric liver transplant recipients suffered from PTSD symptoms, and that non-adherence (non-compliance) to medical management may, in some cases, be associated with these symptoms. Traumatized patients, according to this hypothesis, will avoid taking their medications, because these serve as painful reminders of the disease. They conclude that clinically significant non-adherence, was associated with the full spectrum of PTSD symptoms in this sample. It was especially associated with a high avoidance score, which suggests that avoidance of reminders of the disease (e.g. medications) may be a mechanism of non-adherence. Screening for and management of these symptoms, therefore, may improve adherence. They felt that this novel concept might be applicable to other patient populations, and suggest that addressing PTSD symptoms in medically ill populations may improve treatment compliance.

According to this formulation, some patients who suffer from serious life threatening illnesses are traumatized in a similar fashion to war veterans, and victims of violent crime (and hospital and clinic procedures). These patients avoid reminders of their condition, because thinking about their disease is painful and provokes anxiety, Medications serve as such reminders. Therefore treatment of the associated symptoms may restore adherence in the population.

### **12.1.7 Treatment interventions for PTSD in cancer**

Du Hamel et. al. (2000) describes the use of a trauma-focused intervention (TFI) to reduce symptoms of posttraumatic stress disorder (PTSD) in a 40-yr-old man who was 2 years and 11 months post bone marrow transplantation (BMT) for leukaemia. Prior to the treatment, the subject had flashbacks of the BMT and reported physical sensations such as sweating and chills triggered by reminders of this treatment. After 10 TFI sessions including general and cancer BMT-specific information about PTSD, relaxation training, cognitive coping strategies, systematic desensitization, and relapse prevention, the subject was symptom free.

Cancernet (2001) discusses treatment for PTSD in cancer, indicating that there are no specific cancer PTSD treatments, but that the treatments used for the more traditional PTSDs can be used in this area quite effectively. They stressed that what is highly relevant was that the avoidant responses associated with PTSD often prevented or delayed these individuals from seeking professional assistance.

### **12.1.8 Recognised treatments for PTSD**

Various models have been put forward for the treatment of PTSD.

Perhaps the earliest model was that proposed by Freud (1905) in his original "seduction theory" which emphasised the role of actual sexual abuse in the development of later emotional disorders.

Later, theorists such as Joseph et. al. (1997) have suggested that not all survivors of traumatic events go on to develop severe or chronic distress, and that though the experience of a traumatic event may be a necessary cause, various other psychosocial factors must either mediate or moderate the effects of traumatic events.

The psychosocial perspective which they have adopted on post-traumatic stress reactions brings together the current thinking in social and cognitive psychology relevant to understanding adaptation to a wide range of life-stressors. They note that it is not just what happens to people that is important, but also what it means to those people in relation to their perception of who they are; the world they live in and what their expectations are for the future. For example, Joseph et. al. (1997) argue that: "exposure to traumatic events can challenge the whole meaning of a person's life and his or her sense of purpose. One person might construe an event as a lucky escape from which some benefit has in some way been derived, whereas another person might construe the same event as a catastrophic misfortune which proves that life is meaningless. The effects of the traumatic event on the emotional and behavioural reactions of these two people will invariably be influenced by these different appraisals.

"The importance of understanding the role of psychosocial factors in the development of post-traumatic stress reactions is that, unlike the traumatic event itself, they are potentially modifiable and are therefore possible targets for therapeutic intervention. For example, techniques can be aimed at examining the way in which a person makes sense of the experience and how he or she copes with what has happened." (Joseph et. al., 1997, p.131)

Joseph et. al.'s (1997) model suggests a conceptual framework for planning therapeutic interventions with survivors with post-traumatic stress reactions.

The model contains different components of the adaptation process where it may be possible to intervene, these include:

- 1) Promoting re-exposure to the event and to stimuli associated with the event for reappraisal.
- 2) Promoting reappraisal of the traumatic experience and its meaning and in promoting reappraisal of the emotional states to which appraisals give rise.
- 3) Promoting the direct reduction of emotional arousal.
- 4) Promoting helpful coping strategies to deal with emotional arousal and promoting the reviewing of previously held cognitive styles and rules for living, some of which may be maintaining symptoms through blocking re-exposure, others of which may determine primary traumatic appraisal.

The choice of strategy can be determined by the therapist's formulation of the role played by each factor in an individual's case.

Foa and Meadows (1998) point out that post-traumatic stress disorder (PTSD) is a problem of monumental proportion. The rates of experiencing a traumatic event and developing PTSD

following such events are quite high, and they feel this indicates a critical need for effective and efficient treatments of post-trauma disturbances.

In a review of different types of psychosocial treatments, including hypnotherapy, psychodynamic psychotherapy, and cognitive-behavioural therapies, that have been used to alleviate post-trauma distress.

1) Hypnosis has a long history as a treatment for post-trauma disturbances. Freud (1905), for example, used hypnosis to facilitate the abreaction and catharsis that he felt were necessary for recovery. Spiegel (1993) has also discussed the contemporary application of hypnoses to trauma.

2) A number of concepts from psychodynamic theories have been used in both individual and group therapy for trauma victims. For example, Horowitz (1976) has focused on the concepts of denial, abreaction, catharsis, and stages of recovery from trauma in devising brief treatment for trauma-related distress. Intrapsychic conflict that is thought to arise from the traumatic experience was targeted rather than specific symptoms. A similar approach had been described by Herman (1992).

3) The earliest exposure used to treat post-trauma reactions was systematic desensitisation (Wolpe, 1958). This treatment consisted of repeated and brief confrontations with the feared stimuli, paired with relaxation.

4) Cognitive-behavioural therapy models have also been utilized in the treatment of PTSD. A model incorporating prolonged exposure is introduced which consists of five components (Foa and Meadows, 1998) This includes: information gathering, psycho-education, breathing retraining, imaginal exposure (reliving of the trauma), and in vivo exposure (confrontation with trauma reminders). The two exposure components are considered the key elements of the treatment.

During imaginal exposure, the client is instructed to get comfortable, close his or her eyes, and begin visualising the trauma, narrating it in present tense in as much detail as possible, describing not only what is happening but also relating thoughts and feelings. This continues for about 45 minutes, and the narrative is repeated as many times as needed to complete the practice. Before beginning the exposure practice, the therapist should begin audio-taping so that both the instructions and the exposure itself are on tape, which the client will listen to for homework.

At the end of the allotted time, the client is asked to open her or his eyes and is encouraged to use relaxation skills. The therapist then initiates a discussion of the reliving including the client's reactions to the experience and the therapist's impressions of it. This technique is similar to Wolpe's (1958) systematic desensitisation technique.

Based on their previous research, Kazak, Simms, Barakat, Hobbie, Foley, Golomb and Best (1999) developed a one day intervention program for adolescent survivors of childhood cancer, their parents, and siblings. It is a family group intervention that combines cognitive-

behavioural and family therapy approaches. The goals of the program were to reduce symptoms of distress and to improve family functioning and development. A pilot study of 19 families found that at 6 months follow up, symptoms of posttraumatic stress and anxiety had decreased significantly.

Cohen, Barnes and Ramkin (1995) has which addressed the stages of post-traumatic stress recovery. They suggest the following:

- 1) establishing a safe framework for trauma resolution.
- 2) acknowledging and regulating emotion, helping the trauma survivor make sense of confusing and overwhelming emotional experiences. They discuss reflective writing exercises which allow for ongoing integration of thinking and feeling; and
- 3) Self and relational development and improved functioning and growth.

Bar-Tur and Levy-Shiff (1994) published a case study of a Holocaust survivor who achieved her well-being through the process of review and the mechanism of bearing witness. These enable her to gain a sense of control and mastery by externalising her inner world, using words and actions. Through her ongoing activities and engagement with the past, she could also avoid and control the feelings of helplessness and hopelessness imposed by the reality of old age and nourish her damaged narcissism.

Somer (1994) discusses the 'slow-leak' technique. The therapist can suggest to the hypnotized patient that their toxic feelings and impressions cannot be contained forever and thus should be deliberately allowed to leak in minuscule droplets at a rate that would provide no risk to the survivor. They argue that "some survivors have tried over the years to tell their stories and to express what they were going through. They wrote books, scripted plays, directed productions, painted photographs, composed, all these to stem the overflowing feelings they were trying to express: but not everyone could express their feelings in these ways." (Somer, 1994,p. 93)

#### **12.1.9 Post traumatic growth**

Drawing on some aspects of research and the literature in the field, Tower (2000) puts across a more positive approach. He points out that in spite of our society's images of cancer as a horrible death, more than half of all people contracting cancer today will survive the disease, and it is a fact that a significant majority of all long-term survivors report a quality of life equal to or better than their lives prior to cancer. He feels that there is the possibility of being positively changed by the experience. It is suggested that for many of those who live through the ordeal of cancer and survive, it represents a turning point, a transformation from a life without meaning and directed by the energy of others, to one of purpose, meaning and autonomy.

Cordova et. al. (2001) point out that research that has focused solely on detection of distress and its correlates may paint an incomplete and potentially misleading picture of adjustment to

cancer. Likewise McMillen, Smith and Fisher (1997) feel that the study of growth and perceived benefit after traumatic events has been hailed as one of the most promising directions for stress research.

Calhoun and Tedeschi (2000) see the kinds of post-traumatic growth as falling into 3 general categories:

1. changes in one's sense of self,
2. changes in relationships with others, and
3. changes in one's spirituality or religion.

The phenomenon of positive personal change following devastating events has been recognized since ancient times but given little attention by contemporary psychologists and psychiatrists. In recent years, evidence from diverse fields has converged to suggest the reality and pervasive importance of this process of posttraumatic growth (Tedeschi, Park and Calhoun, 1998).

Several authors have attempted to define post traumatic growth as a concept. O'Leary, Alday and Ickovics (1998) define post-traumatic growth (PTG) as positive changes resulting from negative events, while Schaefer and Moos (1998) defines it as individuals' positive adaptation to life crises.

Alternatively, Calhoun and Tedeschi (2001) found that growth processes facilitated a changed sense of self, changed relationships, existential and spiritual growth.

Victor Frankl (1967) in writing on his own experiences and observations as a holocaust camp survivor wrote: "At each moment the human person is steadily moulding and forging his own character. Thus every human being has the chance of changing at any instant. The basis for any prediction would be represented by biological, psychological or sociological influences. However one of the main features of human existence is the capacity to emerge from and rise above such conditions - to transcend them. By the same token man is ultimately transcending himself." (Frankl, 1967, p. 61)

Tedeschi et. al. (1998) explains that post-traumatic growth (PTG) is both a process and an outcome. It is seen as developing out of a cognitive process that is initiated to cope with traumatic events that extract an extreme cognitive and emotional toll. By contrast, Calhoun, Cann, Tedeschi and McMillan's (2000)'s results showed that the degree of rumination soon after the traumatic event and the degree of openness to religious change were significantly related to post-traumatic growth and more rumination soon after the event and greater openness to religious change were related to more post-traumatic growth.

Calhoun and Tedeschi (1998) point out that though post-traumatic growth can be accompanied by an increase in well-being, distress and growth may also coexist. It is felt that there clearly are some ways in which the clinician may make growth more likely for the client.

Updegraff and Taylor (2000) mention positive outcomes that have been reported in response to stressful life events, such as the perceptions of stress-related growth and benefit. They

found that psychological factors that may moderate the relationship between these stressors and the outcomes, are coping style, optimism and control.

Aldwin and Sutton (1998) provide a developmental perspective on posttraumatic growth and review a series of studies that indicate that early stressful experiences can have positive developmental effects.

Tedeschi (1999), writing in general on Post Traumatic Growth, feels that violence can be a catalyst for personal and social transformation. He mentions certain kinds of rumination that appear to lead to revision of fundamental schemas about the self, others, and the future.

Revised schemas appear to survivors as personal growth that has occurred as a result of having to cope with their trauma, and this is incorporated into a personal narrative that gives meaning to the trauma and consolidates perceptions of growth.

#### **12.1.10 Treatment to encourage post traumatic growth**

Schain (1976) points out that, in a society in which a woman's view of her breasts is highly related to her self-concept, breast surgery represents a social stigma, a physical insult, and an emotional trauma. In attempting to translate a traumatic situation into a potential growth-producing experience, she maintained that counselling must be both reparative and integrative.

Antoni, Lehman, Klibourn, Boyers, Culver, Alferi, yount, McGregor, Arena, Harris, Price and Carver (2001) tested effects of a 10-week group cognitive-behavioural stress management

intervention among 100 women newly treated for Stage 0-II breast cancer. The intervention reduced prevalence of moderate depression (which remained relatively stable in the control condition) but did not affect other measures of emotional distress. The intervention also increased participants' reports that having breast cancer had made positive contributions to their lives, and it increased generalized optimism. Both remained significantly elevated at a 3-month follow-up of the intervention.

Sugarman (1994) offers many practical as well as innovative perspectives to help therapists grappling with the many obstacles to helping traumatized patients transcend their difficulties.

Cordova et. al. (2001) viewed cancer as a psychosocial transition with the potential for positive and negative outcomes. They did a study comparing breast cancer (BC) survivors' self-reports of depression, well-being, and post-traumatic growth with those of age- and education-matched healthy comparison women and identified correlates of post-traumatic growth among BC survivors. Groups did not differ in depression or well-being, but the BC group showed a pattern of greater posttraumatic growth, particularly in relating to others, appreciation of life, and spiritual change.

Cordova (2000) suggested that the range of potential outcomes in breast cancer may be explained, in part, by a social-cognitive processing model of emotional adjustment to traumatic events. This adjustment is facilitated by disclosure and active contemplation of cancer-related thoughts and feelings with supportive others. A supportive environment can enhance positive aspects of well being and promote growth, whereas a social environment that

constrains disclosure will inhibit cognitive processing and increase the likelihood of emotional distress.

While a diagnosis of breast cancer is often difficult, many individuals report growth and improved functioning above that prior to diagnosis. A model of growth was developed by Austin (2001) using a sample of twenty women who went through breast cancer treatment. Products of the analysis were two themes and a model linking eight main categories. The two themes are:

1. Search for positive aspects of the cancer experience; and
2. Understanding and replacing unachieved expectations and goals.

The main categories in the model are:

1. Dealing with crisis;
2. Moving beyond cancer;
3. Examining trauma;
4. How to prevent recurrence and what if it happens again?
5. Cancer is forever;
6. Taking stock of outcomes;
7. Distilling insights and creating wisdom; and
8. Reorganizing self and approach to life.

Manne, Ostroff , Winkel , Fox and Goldstein (2003) concluded that it was important to include significant others in assessments of cancer's impact. Spouses had similar courses in terms of post-cancer growth, and predictors of spouse growth were similar to predictors of patient growth.

Weiss' (2001) study investigated perceptions of personal growth among husbands of women who encountered the stressor events of breast cancer diagnosis and treatment. Most husbands reported both significant negative (78%) and significant positive (85%) consequences. They found that the significant predictors of husbands' PTG were depth of marital commitment, breast cancer as DSM-IV trauma and the wife's self-reported PTG. The more his wife views herself as having made positive changes in her life in the aftermath of the trauma, the more likely the husband is to report such growth as well.

The correct intervention can have unexpected and far reaching results. Cruess, Antoni, McGregor, Kilbourn, Boyers, Alferi, Carver and Kumar (2000) examined the effects of a cognitive-behavioural stress management (CBSM) group intervention on serum cortisol levels in women being treated for stage I or II breast cancer. The patients also reported the degree to which breast cancer had made positive contributions to their lives. They conclude that these findings suggest that positive growth enhanced during a time-limited intervention can influence physiological parameters such as cortisol among women with early stage breast cancer.

### **12.1.11 Trauma debriefing**

Trauma debriefing has been used extensively for the treatment and prevention of post traumatic stress. Manton and Talbot (1991) saw the purpose of debriefing as one of providing comfort, defusing the frightening situation, allowing expression of anxieties, and normalising reactions. They described their approach as one which includes empathic listening, with awareness that people may experience many different emotions, all of which are valid.

Hayman and Scaturo (1993) outline a protocol for debriefing military personnel, although there are clear applications of their protocol to other populations as well. The first general guidance from their procedure is that debriefing should begin as soon as possible so as to help defuse the intensity of reactions and prevent negative coping behaviours from becoming habitual. Second, it is recommended that standardised screening instruments are employed so as to facilitate referral for treatment. Third, they maintain that, throughout the debriefing process, it is essential to reinforce the expectation of returning to pre-combat levels of psychosocial functioning. Fourth, they recommend the use of group sessions for married couples, which might include exploration of the impact of separation and enhancement of relationship skills. In addition, the debriefing should proceed at a speed comfortable for the participants. The protocol involves 12 sessions, beginning with a clarification of the purposes of debriefing and the nature of emotional reactions through to the exploration of the personal impact of combat and homecoming, through to learning about managing moods and resolving current life stressors, and finally, facilitating the impact of the group termination.

In a study which examined 137 consecutive admissions to a burns unit, patients were randomly allocated to either a psychological debriefing group or a control group which received no intervention (Bisson, Jenkins, Alexander & Bannister, 1997). Three months later most of the 137 were interviewed in their homes where they completed several self-report measures. Interestingly, it was found that debriefing did not prevent psychological sequelae. However, it was perceived to be useful by most of those who received it. Furthermore, those who received debriefing were more likely to continue with the research, a finding which the authors suggest points to the important role of debriefing in helping to engage patients in a more comprehensive treatment package. This study may have relevance for the study of non compliance and medical trauma debriefing.

According to Fairbank and Nicholson (1987) and van der Kolk, , McFarlane, and van der Hart (1996) exposure to stimuli related to the trauma is an essential part of treatment. But unlike other treatment intervention strategies which may form part of longer-term support services, i.e: systematic desensitisation and implosive therapy, and which are also based on the principle of exposure, debriefing is concerned with prevention rather than the amelioration of symptoms.

Straker (1987) worked with trauma debriefing in the South African situation during the apartheid era. She felt that the term post-traumatic stress syndrome is a misnomer in the South African context. Individuals living in South Africa's black townships were subjected to continuous traumatic stress. This stress was occasioned by the high levels of violence in the townships, violence which was contributed to by confrontations between (a) the South African

Defence Force and Police and various sectors of the community; (b) black anti-apartheid groups and black right wing vigilantes who were more supportive of the status quo; and (c) inter-group fighting among rival anti-apartheid groups (e.g. UDP and Azapo). This has had numerous implications for treatment, not least of which has been the stress on the single therapeutic interview. The return of a counsellee was never guaranteed and therefore it was vital that each session be complete within itself but still offer the potential for follow up.

Straker (1987) felt that involvement of adolescents as active participants in their own treatment programmes were especially important in the South African context politically. In contrast the adolescents perceived themselves as active and defiant and as being at the forefront of resistance. There was a great crisis of confidence in authority at this time and while in the 1990's the generation gap has been partially bridged the idea of authority dictating anything to the adolescent including a treatment programme is an anathema. They demanded full participation in decision making processes and demand to be seen as adult and responsible. She therefore requested this group to participate in generating their own treatment programme by sharing their perceptions of township conditions and their consequences was an important prelude to a discussion of more personal issues.

It is suggested that especially when the cancer treatment has taken on the nature of a chronic disease some cancer patients could suffer from "continuous " traumatic stress.

There has been some conflict about the efficacy of some methods of trauma debriefing. For example, in a study by van Emmerik, Kamphuis, Hulsbosch and Emmelkamp (2002) their

meta-analysis of group trauma debriefing which is done within the first six months following trauma, seems to cast doubt on the efficacy of trauma debriefing.

Hyer, Woods, Bruno and Boudewyns (1989) administered the Millon Clinical Multiaxial Inventory (MCMI) to 50 Vietnam veterans with PTSD prior to and following an intense 5 week treatment that focussed on the revived Vietnam experience. Results show that 17 of 20 scales on the MCMI changed in the negative direction as a result of treatment, indicating that this treatment was not effective with this population.

Stuhlmiller and Dunning (2000) challenge some of the basic concepts and beliefs surrounding debriefing. They describe its evolution from military to civilian settings (emergency workers), and then its rapid expansion as a panacea for all trauma experiences. They hypothesize that debriefing has evolved in a medical or pathologizing model and that its processes may encourage pathology outcomes in a process of medicalization of normal life experience. Debriefing has evolved in a technological age, as a technological solution. They go on to discuss the impetus of its popularization. The authors also contest the universal application of debriefing, suggesting that this is inappropriate, as all events, even the most traumatic, do not universally lead to morbidity or post-traumatic stress disorder (PTSD). They explore the potential for positive processes, resilience and growth and the possibility of a salutogenic approach to intervention.

Violanti, Paton and Dunning (2000) argues in similar fashion when discussing psychological debriefing techniques to help prevent post-traumatic stress disorder. It is pointed out that

while debriefing is said to be important, mental health professionals are uncertain about outcomes, and there is agreement that debriefing may be somewhat hindered by its pathogenic nature rather than being a positive method for preventing trauma stress. Violanti, Paton and Dunning (2000) suggests that by concentrating on alternative ways of thinking about patterns of interaction between people and adversity, the adoption of a salutogenic paradigm for conceptualizing, researching, designing, and delivering effective trauma intervention is advocated. This paradigm offers opportunities for intervention to mitigate traumatic stress reactions, develop resilience, and establish necessary individual and organizational resources.

Also the pathologising and exacerbating of PTSD has been compounded in situations where legal claims of compensation are made following traumatic experiences.

#### **12.1.12 Trauma debriefing as a preventive intervention for non-compliance**

Tones and Tilford (2001) discuss compliance in preventative medicine. They comment that the language of compliance and adherence are still well represented in the literature alongside considerations of ways of achieving active participation of patients. They point out that the training of some professionals, nurses most probably, has been extended to incorporate an emphasis on positive health and health promotion. They also mention the concept of a preventative health promoting hospital. In this respect, medical trauma debriefing could become part of this to enhance health habits and minimize non compliance. The concept of early or later medical trauma could potentially even be added to "Risks to health" in a future WHO report (WHO 2002).

Ewles and Simmet (2001, p. 45) in their book on preventive medicine talk of "Aiming for Compliance or informed choice?" Symptoms of PTSD might take away the ability to an informed choice e.g. with a dental appointment, the patient may say: "I know I should have attended but I was too scared".

Trauma Debriefing has been used extensively especially in South Africa, to deal prophylactically preventive in potentially post traumatic stress producing situations. In this study a model has been worked out of Medical Trauma Debriefing, in this instance, obviously geared towards the traumatic experience of cancer.

As has been mentioned, Medical PTSD is a relatively new concept, and has only been made possible after its inclusion into the DSM IV (American Psychiatric Association, 1994; Shemesh et. al., 2001).

Trauma Debriefing, or, in this instance, Medical Trauma Debriefing, which formed a major part of the intervention suggested and used in this study would treat the trauma before symptoms would surface. In other words, just as is done in South Africa and in other countries following crime, war and terrorism, the individual was given medical trauma debriefing as a prophylactic measure. It is suggested that Trauma Debriefing, as a preventative measure, should have a positive impact on compliance.

Two models have been used in the making of the hybrid form of the Wits Trauma Intervention Model (Eagle, 1998). While the main model is that of Eagle (1998) some aspects of the

Trauma Incident Reduction (Bisbey and Bisbey, 1998) which were deemed to relevant to medical trauma debriefing, are also used. A brief description of these will be given before discussing the Intervention used in Phase 2 of this research:

#### **12.1.12.1 The Wits Trauma Intervention Model (Eagle, 1998)**

Eagle (1998) asserts that post-traumatic stress represents a disorder in which dysfunction occurs both internally and externally, according to Freud at the interface of these two aspects of psychological functioning ie: at the ego boundary. Disturbance manifests in recognisable cognitive, behavioural and somatic symptoms and in addition carries unconscious associations and anxieties. She sees that the ideal approach to treatment thus appears to be to draw on the relative strengths of both the psychodynamic and cognitive-behavioural schools.

She discusses the massive psychic disruption which involves an attack on ego-coherence and experience of the 'death imprint' (Lifton, 1993).

On the one hand, the psychological distress arises out of a 'real' externally tangible stressor and reaction to this kind of traumatic threat evokes largely universal and coherent symptoms/responses, in keeping with DSM III-R and DSM IV definitions of post-traumatic stress (American Psychiatric Association, 1987 and 1994), some of which are physiologically based. On the other hand, the nature of traumatic stress (involving as it does threat of death, physical harm or exposure to the grotesque (American Psychiatric Association, 1994), almost inevitably evokes primitive responses linked to unconscious fears, threats of overwhelming

impulse life and inchoate fantasies. As Eagle points out, Freud's deceptively simple description of traumatic stress as arising as a consequence of 'an extensive breach being made in the protective shield against stimuli' (Freud, 1920/1955, p.31), cogently highlights this attack on the interface between the internal and the external world of the survivor. It is this characteristic of traumatic stress pathology that lends it so ideally to integrative intervention.

The 'Wits Trauma' model was originally conceived primarily within a psychodynamic framework. However, it soon became apparent that understanding responses to traumatic threat primarily within the framework of persecutory anxiety and pre-existing personality dimensions had limited validity. Intervention required structured and problem-orientated practices beyond the subjective understanding of the meaning of the experience for the individual. Thus, a model evolved which Eagle (1998) claims can retrospectively be understood as representing a synthesis of understanding derived from both psychodynamic and cognitive-behavioural perspectives. This synthesis has validity not only in terms of the assertion that trauma impacts dramatically on both internal and external psychological functioning, but also in terms of comprehension of the mechanisms of damage and repair (Eagle, 1998).

In psychodynamic terms, treatment aims to prevent the use of repression as a defence leading to the possibility of neurotic symptom formation (Freud, 1915/1957) and the therapist is also invested in protecting the person against further regression given the overwhelming assault of traumatic exposure on ego functioning (Freud, 1920/1955). From a cognitive-behavioural perspective, the therapist wishes to prevent the development of phobic avoidance initiated by

what could be considered a powerful classical conditioning experience, stimulating associations between intense anxiety and various features of the traumatic situation (Kilpatrick, Veronen and Resnick, 1979).

The model itself includes five components which can be introduced interchangeably within the intervention depending on the needs of the client and the natural flow of the session/s.

1. Telling/re-telling the story.
2. Normalising the symptoms.
3. Addressing self-blame or survivor guilt (restoring self-respect).
4. Encouraging mastery.
5. Facilitating creation of meaning.

#### **12.1.12.2 Traumatic Incident Reduction (TIR)**

Bisbey and Bisbey (1998) give the approach of Traumatic Incident Reduction as a Brief Therapy Approach for Post-Traumatic Stress Disorder.

Traumatic Incident Reduction (TIR) was developed by an American psychiatrist, Frank Gerbode, in 1986. They used the term person-focussed instead of person-centred in order to distinguish their orientation from the school of person-centred counselling developed by Carl Rogers. To them, person-focussed means that they consider any individual to be the expert on

this own experience. He is the only one who can fully understand his experience - decide what it means, how it fits in the context of his own life and how it translates into his relationship with others. They point out that this is a central principle in TIR. The client's own expertise is respected and this informs the therapists practice. Information is gained from the clients to help the therapist guide them in examining their worlds in manageable pieces so that they can make sense of the whole." (Bisbey and Bisbey 1998)

The central concepts of TIR include:

1. exposing the client to the trauma repeatedly,
2. structuring the session closely,
3. proceeding with work on a trauma or a group of related traumas in (preferably) one session until resolution (an end point) is reached.

Structured techniques that are made up of questions and instructions.

Use of a defined end point (e.g. with specific criteria that depend on the process of the session rather than the content) to determine when to end the session. (an unfixed session time rather than a 50-minute or 90-minute session).( Bisbey and Bisbey 1998 Pgs 1,2)

Bisbey and Bisbey (1998) point out that in the field of trauma work, it is generally agreed that the methods that best enable a client to resolve traumatic experiences usually involve some form of exposure to the traumatic memories and the emotions, thoughts and sensations associated with these memories. They point out that by exposure, They usually mean that the client is asked to review the traumatic memory and talk about it, write about it, act it out or use art work to express the memory. Most forms of exposure-based work involve the client examining the memory in depth. In TIR, this exposure is accomplished through having the

client review the trauma silently from beginning to end, and then tell the counsellor what happened. The client is asked to do this repeatedly until an end point is reached.

Consequently, exposure lengths must be long enough to allow the trauma to lose some of its emotional intensity. Ideally, they should be long enough for the trauma to lose all of its emotional intensity. (Bisbey and Bisbey 1998 Ninety minutes was chosen because research on imaginal flooding (a behavioural exposure-based treatment) indicated that 90 minutes usually allows enough time for the emotion to reach its peak and then begin to drop significantly so that, at the end of the session, the level of negative emotion is less than it was at the beginning of the session, thus not re-traumatising the client. An end point is the point at which the trauma (or group of traumas) being examined is considered to be resolved. There are specific factors that the counsellor must observe in the session before he considers the session to be at an end point. (Bisbey and Bisbey 1998)

"The basics of a TIR session involve having the client choose an incident to work on; identify and tell the counsellor when the incident happened and where it happened; identify and tell the counsellor how long the incident lasted; identify and tell the counsellor where he was at the time of the incident; find the beginning of the incident, review the incident from the beginning to the end in his mind, and then tell the counsellor what happened (which includes the story of the incident, the thoughts, feelings, sensations during the incident and the thoughts, feelings, sensations during the reviewing of the incident, and any associations or conclusions the client draws from this experience). The client is asked to review the incident repeatedly and tell the counsellor what happened until an end point is reached, his attention is drawn to an earlier incident or to further change (in content of the story, affect or thoughts about the story) occurs

in the session. If an end point is reached, the counsellor ends the session. (Bisbey and Bisbey 1998 Pg 16-18)

## **12.2 Hypothesis**

The second phase of this study was to identify ten or more potential non compliant patients and place them on a psychotherapeutic program to address possible personality (or avoidance/traumatic) contributors which may lead to non compliance, and circumvent these.

## **12.3 The Subjects Used**

Forty five patients were given the MCMI-II and 11 patients were selected on the results of this as potentially non-compliant and willing to come for the psychotherapeutic intervention.

As has been discussed, each trait stands on its own merit as a significant pointer towards non-compliance. It was for this reason that two of the patients © and E, see Table 10) in the 2nd Phase were chosen on the basis of having at least two of the traits brought up by the Kruskal Wallace test as significant at the 5% level even though their results on the model were not significant. It must be noted that these patients were already showing objective signs of non-compliance with their cancer treatment. The other eight patients were chosen on the basis of the Prediction Model that was calculated on the basis of the stepwise regression analysis.

The following table (Table 10) is produced by the Prediction Model when put into a Microsoft Excel program to more easily identify Non Compliant patients. As mentioned, patients C and E were shown on the model to be compliant. However as has been stated in the results of Phase 1, though the non-compliant patients were sorted correctly by the model 72.73% of the time, this was not so for the compliant patients and therefore there was room to use the traits found significant by the Kruskal Wallis Test especially as the patients were showing signs of non- compliance.

TABLE 10

## SUBJECTS HIGHLIGHTED BY THE PREDICTION MODEL USED IN THIS PHASE

|   | DEBAS | SZTYP |            | O      | Model Classification |
|---|-------|-------|------------|--------|----------------------|
|   |       |       | Compliance |        |                      |
| A | 77    | 81    | -0.575     | -0.575 | Non-compliant        |
| B | 52    | 67    | -0.151     | -0.151 | Non-compliant        |
| C | 48    | 53    | 0.206      | 0.206  | Compliant            |
| D | 59    | 65    | -0.161     | -0.161 | Non-compliant        |
| E | 55    | 52    | 0.177      | 0.177  | Compliant            |
| F | 82    | 71    | -0.418     | -0.418 | Non-compliant        |
| G | 95    | 60    | -0.245     | -0.245 | Non-compliant        |
| H | 92    | 95    | -0.869     | -0.869 | Non-compliant        |
| I | 45    | 71    | -0.173     | -0.173 | Non-compliant        |
| J | 85    | 111   | -1.052     | -1.052 | Non-compliant        |
| K | 61    | 66    | -0.196     | -0.196 | Non-compliant        |

TABLE 11

## AGE RANGE OF THE ELEVEN SUBJECTS

| AGE RANGE | NUMBER OF SUBJECTS |
|-----------|--------------------|
| 21 - 30   | 1                  |
| 31 - 40   | 3                  |
| 41 - 50   | 2                  |
| 51 - 60   | 1                  |
| 61 - 70   | 4                  |

As can be seen, the majority of patients were between 31 and 50 years of age, though there was a peak between 61 and 70 years.

TABLE 12

## DISTRIBUTION OF SUBJECTS ACCORDING TO CANCER TYPE

| TYPE OF CANCER             | NUMBER OF SUBJECTS |
|----------------------------|--------------------|
| Testicular Cancer          | 2                  |
| Leukaemia                  | 1                  |
| Breast Cancer              | 2                  |
| Basal Carcinoma of the Ear | 1                  |
| Malignant Caecum Polyp     | 1                  |
| Melanoma                   | 1                  |
| Lymphoma                   | 3                  |

Three of the patients had Lymphoma, a majority, as in the original study. Two had breast cancer and two with testicular cancer.

TABLE 13

## SEXUAL DISTRIBUTION OF SUBJECTS

| SEXUAL DISTRIBUTION |         |
|---------------------|---------|
| MALES               | FEMALES |
| 4                   | 7       |
|                     |         |

There are more females than males in this group.

## 12.4 Procedure

Each patient was given an Individual Medical Trauma Debriefing

Session and the effectiveness of the results was assessed.

This was done on the basis of:

Return to or the continuation of treatment

Change in attitude towards compliance

Emotional relief after the intervention

## 12.5 Materials

### 12.5.1 Instrument used as an intervention: a hybrid adaptation of the wits trauma intervention model (Eagle 1987)

(Added to this are several aspects of motivational suggestions towards treatment

Compliance)

The treatment would consist of one session lasting about 90 minutes, with the possibility of more if the patient wants it. Exposure lengths must be long enough to allow the trauma to lose a great part of its emotional intensity.

The single therapeutic interview: "The return of a patient is never guaranteed and therefore it is vital that each session be complete within itself but still offer the potential for follow up ". (Straker, 1987; Bisbey and Bisbey, 1998)

The introduction is in the form of a validation, where the patient is invited to agree with the statement that the trauma of a life threatening illness is in its own way as traumatic as a hold up or a hi-jack etc. It is then mentioned that recent research is pointing in this direction.

Trust has to be established. The patient is told that the therapist has worked with many patients like him or herself and that he is obviously not alone in this predicament. Thus the therapist offers ego support by expressing a willingness to look, together with the patient, at what has happened. (Straker, 1987)

As with Bisbey and Bisbey (1998) the therapy is person-focussed which means that we consider any individual to be the expert on this own experience. He is the only one who can fully understand his experience, decide what it means, how it fits in the context of his own life and how it translates into his relationship with others.

The therapist has to be present in a very empathic way. He/she cannot remain aloof and cool but must be prepared to share in the victim's grief and horror and by being supportive and available, provides a buffer against the interviewee being overwhelmed by painful affect. (Straker, 1998)

The method used will be outlined here but the full format of the intervention is to be found in Appendix 9.

#### **12.5.1.1 Telling the story**

This involves detailed description of the experience of cancer in sequence including facts, feelings, cognition and sensations. Fantasized and imagined aspects are also solicited as well as cancer misconceptions and cognitive distortions around the illness and treatment as applied to themselves.

The person is encouraged to recall in detail everything he can and the therapist is present as a witness to this process through active listening , empathic reflection and appropriate questioning. This therapeutic space becomes a transitional space (Winnicott, 1971) in which the experience is relived in the realm of the symbolic rather than the actual. This exposure technique can also reduce anxiety (desentization).

#### **12.5.1.2 Normalizing the symptoms**

The patient is encouraged to discuss the similar impact of trauma on others and not only on him/her self. In this way the realization comes that this is shared with people undergoing similar treatment. The patient would be given a description and education of PTSD symptoms as well as other reactions such as depression, guilt and shame.

#### **12.5.1.3 Addressing self blame or survivor guilt**

Patients have many cognitive distortions about themselves, their abilities and their reactions and are often filled with self blame, spurred on by their punishing superegos. In this part of the session, patients are taught to identify their dysfunctional automatic thoughts.

#### **12.5.1.4 Promoting mastery**

The patient would be taught to replace negative, debilitating cognitions with positive, self enhancing thoughts and actions.

Efforts would be made to desensitize the person to the fear of Chemotherapy.

#### **12.5.1.5 Facilitating the creation of meaning**

The person's belief system is engaged and he/she is encouraged to look for meaning beyond him/herself. Goals, even short term ones can be defined. Certain perceptions can be changed and reframed, such as the difference between the cancer VICTIM and the cancer SURVIVOR.

### **12.6 Results**

Eleven patients who were found to have the potentially non-compliant protocol on the trauma debriefing scale were given the Medical Trauma Debriefing Intervention.

This was deemed to be very successful in 8 instances and successful in another two. Only one case was deemed unsuccessful where despite the intervention the non compliant behaviour continued.

### 12.6.1 Table 14

#### Compliance before and after the medical trauma debriefing intervention

| PATIENT | OBVIOUS PRE NON COMPLIANCE | POST NON COMPLIANCE | POST FAIR COMPLIANCE | POST GOOD COMPLIANCE |
|---------|----------------------------|---------------------|----------------------|----------------------|
| A       | x                          | x                   |                      |                      |
| B       | x                          |                     |                      | x                    |
| C       | x                          |                     | x                    |                      |
| D       |                            |                     |                      | x                    |
| E       | x                          |                     |                      | x                    |
| F       | x                          |                     | x                    |                      |
| G       | x                          |                     |                      | x                    |
| H       | x                          |                     |                      | x                    |
| I       | x                          |                     |                      | x                    |
| J       |                            |                     |                      | x                    |
| K       | x                          |                     |                      | x                    |

Pre-non-compliance is non-compliance before the trauma debriefing intervention.

Post-non-compliance/compliance is non-compliance/compliance after the trauma debriefing session.

Post-non-Compliance - The patient attended less than 20% of their treatment or follow up sessions.

Post fair compliance - The patient attended between 60% and 70% of their treatment or follow up sessions.

Post good compliance - The patient attended between 80% and 100% of their treatment and follow up sessions.

Besides having the non compliant protocol on either the discriminant model or the Kruskal Wallis Test:

Out of 9 patients who were objectively non-complying before the intervention:

1 was still not complying after the intervention

2 were complying fairly well after the intervention

6 were complying well after the intervention.

### **12.6.2 Type of cancer and the change in behaviour after the intervention**

**(See table 15 - Appendix 10)**

Patient A had leukaemia. After getting over the initial severe shock of his diagnosis he attended follow up sessions for a few months and then disappeared from treatment for three

years. He started attending follow up appointments again during the time of the intervention but two years later had again dropped out of treatment.

Patient B had testicular cancer. He had initially only presented himself for treatment after walking had become difficult. He had also dropped out of follow up treatment feeling that he felt well and did not want to attend. After the intervention he again attended follow up appointments rigorously.

Patient C had melanoma. She was only rarely attending follow up appointments with time spaces far exceeding the advice of her skin specialist. After the intervention she started to attend more regularly.

Patient D, had breast cancer. She had not shown obvious signs of non compliance and after the intervention showed excellent compliance, eventually having a breast reconstruction.

Patient E had lymphoma. Before the intervention she had had difficulty in complying and had a lot of resentment towards the medical profession because of their delay in making a diagnosis and following it up. After the intervention her compliance on all levels was excellent.

Patient F had lymphoma. She had not complied with treatment and when contacted had decided to halve her chemotherapy medication as she knew her own body and felt that was

what she needed. After the intervention she complied fairly well though she was at times minimally late for her follow up appointments.

Patient G had a malignant caecum polyp and was not attending her recommended follow up appointments and had more or less dropped out of therapy. After the intervention she attended these regularly and did the required colonoscopies.

Patient H had breast cancer. Before the intervention she had on several occasions wanted to drop out of her vigorous therapy schedule. After the intervention she became far more settled and was careful to continue and to keep all her appointments.

Patient I had basal carcinoma of the ear which she was neglecting in that though she knew it was possibly cancer she had not consulted a doctor. After the intervention the diagnosis was confirmed, part of the top of the ear was removed and she has carefully attended follow up appointments.

There was no obvious non-compliant behaviour with patient J, although he was finding everything very traumatic. He was cooperating with treatment after the intervention but died between follow up sessions from a disease (COPD) not related to the Cancer.

Patient K wanted to drop out of therapy and use some kind of alternative magnetic resonance therapy. After the intervention he returned to conventional treatment and complied well. However he died by haemorrhage during a course of chemotherapy.

### **12.6.3 Specific aspects of trauma debriefing**

Patient A, B, E, H and K's trauma debriefing was focussed on the present illness of cancer.

However Patients C.F.I and J needed trauma debriefing for the present illness of cancer but also trauma debriefing for their previous history of medical trauma.

Patient D needed trauma debriefing for her present illness of cancer but also debriefing for her vicarious traumatic experience of her husband's fatal cancer.

Patient G needed trauma debriefing for her present illness of cancer but also debriefing for her son's illness and death.

Although Trauma Debriefing for previous medical conditions or vicarious trauma debriefing for cancer of other life threatening illnesses in close relatives was combined with trauma debriefing for the present illness of cancer, it in no way distracted from it but was rather a natural flow of circumstances affecting the present condition.

All eleven patients felt they had benefited from the trauma debriefing session. In 10 of them their attitude towards compliance had changed.

## 12.7 Discussion

1. Eight out of 11 patients identified as potentially non compliant responded positively to trauma counselling.
2. It is clear from this small pilot study that trauma counselling should be considered as part of an approach to combat non compliance in cancer patients.

Shemesh et. al. (2000 and 2001) have pioneered this field and, especially in their 2000 study of PTSD and non-compliance in Paediatric Liver Transplant patients, where they conduct an intervention on some of the patients in the study, some comparisons can be made with this one.

The three cases they described in detail in their study became adherent to their medications when symptoms of PTSD subsided during the course of therapy. An interesting factor was that they targeted the PTSD rather than the non-compliance and the non-compliance improved as of itself in response to this.

They make a significant comment about the measurement of adherence in the context of an intervention for PTSD. They say (Shemesh et. al., 2000, p.2) "There is significant controversy regarding the definition and measurement of non-adherence, and no gold standard is available. It is possible that some degree of non-adherence is acceptable. We did not attempt a

comprehensive evaluation of non adherence in our study population. Rather we attempted to elucidate whether patients who suffer from PTSD are likely to be clinically non-adherent (i.e. non-adherent to the point that their health is in danger). We were interested in measures of non-adherent behaviour over time. "e.g. Regarding the improvement in a patient after the intervention they mention that the mother reported that a young patient was definitely feeling better and then she immediately stated that " he is now taking his medicine as prescribed," which they team found interesting as, as was mentioned before, they had treated the PTSD and had never actually addressed the non-adherence.

In this study the link between PTSD and a reduction in being able to use the cancer treatment program adequately was openly stated. An interesting factor was that the patients seemed to feel, somehow validated and relieved that the traumatic factors connected to their illness and treatment was recognized. This was considered an important factor in their treatment.

There were two patients in the present pilot study group suffering from breast cancer:

As has been shown, recent literature has given strong indications of PTSD in breast cancer (Cordova et. al., 1995; Pitman et. al., 2001; Roper, 2000).

Naidich's (1997) finding that women diagnosed with breast cancer displayed unequivocal symptoms of PTSD, included intrusive thought and avoidance behaviour related to breast cancer stimuli. She further noted that medical treatment for the disease necessitated repeated exposure to potentially traumatic stimuli.

This is further aggravated by the experience of mastectomy (Khalid and Gul, 2000). (One of the patients in the group had a lumpectomy and the other a mastectomy).

Andrykowski et. al.'s (2000) research suggested that women with greater PTSD symptoms at the initial interview were less likely to participate in the follow-up interview, which relates directly to non-compliance, the woman becoming so traumatized that her avoidance would heighten and she would begin to avoid the treatment centre. He also found that PTSD symptoms in these patients did not diminish over time.

Two unforeseen factors emerged in medical trauma debriefing which are important for further research.

1) Previous medical trauma can influence the level of trauma in the patient besides the present illness, perhaps even since childhood, which appeared to have caused some kind of trauma or at least avoidance responses. It was important that this was dealt with, as a particular attitude to doctors and medicine, usually a negative one, can be set at this time.

Tjemsland et.al. (1996a) in their study found that the level of acute post-traumatic stress response to breast cancer surgery seemed best predicted by pre-morbid variables relating to stress.

In another report, however, Tjemsland et.al. (1996b) found that previous physical and psychiatric health parameters showed no association to acute traumatic stress symptoms except for those who had experienced a "serious illness/accident/hospitalisation last year" who had some more avoidant symptomatology, which possibly related to traumatizing and re-traumatizing. Avoidance would, obviously, lead to non-compliance.

The above finding of 'within the past year' is possibly an isolated one. Erikson and Steiner (2000) and 'Anonymous' and Steiner (1999) pointed out that years after treatment, the relatively high levels of current PTSD and trauma associated symptoms reflect the long term deleterious impact of having cancer as a child.

Wintgens et. al. (1997) discusses posttraumatic stress symptoms and treatment in children after diseases such as cancer, organ transplantation (see also Shemesh et. al., 2000), and severe burns. They believe that many aspects of severe childhood diseases are traumatic and triggers of stress. There are an increasing number of studies showing the traumatogenic aspects of childhood cancer (Kazak et. al., 1996; Erickson and Steiner, 2000 and 2001; Davidson, Inslicht and Baum, 2000).

## 2. Vicarious trauma such as the life threatening illness of a spouse or a child or close relative.

This could be present in the patient and has to be dealt with. In the instance of one of the subjects with a doubt as to whether the compliance would be sustainable, the woman had watched her husband die of lymphoma and had lost all faith in doctors, which was severely hampering her own treatment.

Often the illness, especially cancer, of a close relative such as a spouse or child can cause vicarious trauma which can influence compliance when the person him/herself becomes an oncology patient.

It is clear from the literature that parents vicariously experiencing their children' cancer are very prone to PTSD and traumatic stress symptomatology (Darbasie, 2000; Niles, 1996; Kazak et. al.,1998; Barakat et. al., 1997).

The patient for whom Trauma Debriefing did not seem to work was a woman age 43 with non-Hodgkins Lymphoma. She was not really cooperative. She stated before the session that she was going to halve her medication and when I she was asked if the oncologist had agreed she said that she knew her own body better than the doctor did and she felt she now only needed half. She did not keep appointments adequately for any of the hospital clinics. The intervention did not seem to have been more than minimally and temporarily effective.

## **12. 8      Limitations of the Study**

The questionnaires demanded that the patients be very proficient in English , which limited the study considerably in both phases 1 and 2.

The results of the MCMI2 with the predictive model has excellent potential for a fairly educated population who are able to fill in and understand the 175 item questionnaire. To use this in South Africa among many members of the population is impossible.

For the above reason, there were a vast number of potentially non-compliant oncology patients who could not be assessed.

At the beginning of the study the link between PTSD and non-compliance had not been identified. Future studies would be able to include an actual PTSD scale in the battery of questionnaires.

The number of people given the Medical Trauma Debriefing was only ten which is a small pilot study sample. This simply gave a very strong indication that Medical Trauma Debriefing should be studied by as many researchers as possible to see if it can become a successful prophylactic intervention for medical non-compliance.

## **12.9 Conclusions**

These results are preliminary. However, they have the potential to develop a new concept in Medical Treatment and its interface with Psychology and Psychiatry. Further intensive research in this field could possibly see medical trauma debriefing as a powerful tool in controlling non-compliance.

Medical non-compliance is a vast problem which is becoming a top priority with medication which depends on almost 100% compliance such as the new medicines for HIV/AIDS. Shemesh et.al.'s (2000, 2001) suggestion that it is possible that some degree of medical non-compliance is acceptable would have no place in HIV treatment.

A model emerged from this research from the MCMI-11 that could predict non compliance in oncology patients with a good prognosis 72.5% of the time; i.e. in the interaction between the debasement and schizotypal traits. In another statistical procedure, also from the MCMI-11, the disclosure, debasement, avoidance, passive-aggressive, self-defeating, Schizotypal, anxiety, dysthymia, alcohol dependency and major depressive traits were found to be significant at the 5% level and schizoid, borderline and drug dependency traits were significant at the 10% level.

Some of the latest research (Shemesh et. al., 2000 and 2001) has highlighted its relationship to medical post-traumatic stress.

Only when the DSM-IV (American Psychiatric Association, 1994) was brought out, did the diagnostic category of PTSD make room for PTSD in serious or life threatening medical conditions and from that time a fair amount of research has been reported especially in the field of cancer and PTSD.

Research on the MCMI-I and MCMI-II and PTSD, in various populations, has found almost identical significant traits to those found in this research in the non-compliant patients, and it was decided to do a trauma-based intervention. It was not to be purely an intervention for treating PTSD but rather an intervention which could have a preventative effect on PTSD and therefore on non-compliance.

Trauma Debriefing could then be found to be an effective intervention in all fields of medical non-compliance. Therefore, this study used an intervention of a single trauma debriefing session, lasting about 90 minutes (with the possibility of more sessions) which is an adaptation of the Wits Trauma Intervention Model ( Eagle, 1998) and other Trauma models such as that of Bisbey and Bisbey (1998) . This could go through the trauma not only of the present illness, but other medical traumas, even from those from childhood. This intervention runs through several stages such as: telling the Story, normalizing the (psychological) symptoms, addressing self-blame or survivor guilt, and promoting mastery.

Such an approach could potentially be used for post heart attack patients, accident patients, bypass surgery patients, and others. It is postulated that this should improve compliance in all these areas. In this present study research has been conducted into trauma debriefing in Oncology patients with tentatively good results. Medical Trauma Debriefing has the potential for acceptance as part of the recovery process from serious, life threatening or traumatic illness.

Obviously there are endless prospects in Medical Trauma Debriefing which would go beyond the actual diagnosis of actual PTSD but would address at least partially the avoidance aspect which is clearly a factor in non-compliance.

At the beginning of this thesis, a lot of research has been included on non-compliance in other medical fields besides the field of oncology. The DSM-IV (1994) opens the diagnosis of

PTSD to any life threatening illness. There is also the aspect of an illness perceived by the patient (or his relatives) to be life threatening which could, then, have the same effect. There also seems to be room for traumatising in other medical procedures, (Shemesh et. al., 2000 and 2001) especially with children where avoidance would come into play very strongly. One could go into the early work of the behaviourists to find this clearly stated where the traumatized person would need systematic desensitization or other kinds of conditioning to cure this (Wolpe, 1973).

If one takes the fairly simple medical trauma of a child going to a dentist and suffering a fair amount of pain together with the fear and helplessness of not knowing what the dentist is "going to do next", he can be extremely resistant about going to the dentist the next time and will do everything he/she can to evade the appointment until he is somehow 'dragged' there by his parents.

It is also suggested that trauma can be experienced in a psychiatric illness, for instance, a manic attack or some kind of psychotic episode. Apart from the actual psychiatric conditions, there is the stress of not being able to distinguish fantasy from reality and the feeling of "going mad" which precedes this, (before the patient loses insight). This is followed by the recovery which and an awareness that time has passed where the person has not known what has happened or what they have done, which can be extremely traumatic. This would require a particular type of trauma debriefing so that the person would not 'shrink' from all psychiatrists and would keep on with their maintenance medication.

From this research it seems that studies in this field could make a great deal of difference to patients and to compliance. Though a great deal of further research is needed, the suggestion is put forward of using Medical Trauma Debriefing as a preventative measure in all the medical interventions or diseases which could potentially cause PTSD and therefore non-compliance.

It is suggested that Trauma Debriefing, as a preventative measure, be incorporated automatically and routinely into the treatment of certain medical and surgical conditions.

#### **12.10 Suggestions for further Interventions and Research**

As mentioned previously, as these results are in many ways preliminary, there is a need to pursue the effectiveness of medical trauma debriefing in all aspects and fields of medicine. This study made it clear that non compliance is a problem in virtually all areas of medicine. Recently there has been an urgent call for effective interventions especially with HAART in HIV/AIDS. In this respect the situation has become urgent. Medical Trauma Debriefing could well be the solution.

This could apply to Orthodontic treatment with children a program that educates and a group that deals with the stress (pain, friend's attitudes; self image etc.). More suggestions are Post Stroke (or Post Cardiac Incident) Trauma Debriefing Post operative trauma debriefing and Post life threatening infection (meningitis, peritonitis etc) trauma debriefing.

Another important area which has to be continued is to put out literature on a level of popular reading. The patients rarely read the medical journals but read avidly the books on popular psychology and medicine, and would far rather read the popular magazines than the medical journals.

It becomes urgent to enter the field of popular journalism in order to put across the messages that are health and life saving in medicine. The patients seldom read the journals. Examples of popular books making a great impact but written at the highest academic level are Burns (1999) and Holland (2000).

What is needed are peer reviewed (by authoritative and reliable physicians and social scientists) popular articles and books which would bring things across to the man in the street who wants to weigh the evidence and make his own decisions.

Regarding the Schizotypal aspect of the non compliant patient, and the tendency of people with strong Schizotypal traits to pursue the alternative, the spiritual and Traditional Medicine routes, it is important to have some understanding of these fields. It is also important to have some connection with practitioners in these fields as, in many instances, these constitute the first contact in the treatment programme.

As was highlighted at the AORTIC 4th International Conference on Cancer in Africa, in Ghana, October 2003, practitioners of Traditional Medicine should be approached, with respect, to establish some kind of cooperation in the treatment of mutual patients.