PSYCHOSOCIAL CARE FOR PEOPLE WITH CANCER: THE 'VICTIM'S' PERSPECTIVE

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"I've been around you know...I have seen boys like these, younger than these, their arms torn out, their legs ripped off, but there is nothing like the site of an amputated spirit. There is no prosthetic for that."

- Al Pacino as Lt. Col. Frank Slade in 'Scent of a Woman', Universal Pictures.

Politely, but firmly, a person with cancer returns her questionnaire to the researcher, and states;

"I am not that type of person."

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Abstract

Most psychosocial services for people with cancer remain under-utilised. This phenomenon disturbs the logic of two facts: that people with cancer do experience psychosocial problems, and that most interventions are capable of alleviating psychological distress and improving quality of life. This dissertation approached the above problem using a multi-modal methodology. First, a multi-choice questionnaire survey was conducted at the out-patient oncology clinic, Groote Schuur Hospital, showing that interest in the more professionalised services such as psychiatry, psychotherapy, coping skills courses, and social work was low, while interest in less professionalised services such as self-help groups and veteran patient visits was relatively high. In the context of the narrative and discursive approaches to understanding human experience, it was argued that psychosocial oncology presents a particular view of the person with cancer, rooted in positivist and medical frameworks, which may be out of sink with patients' own understandings of themselves. A discourse analytic study, using two focus group interviews and four individual interviews with people with cancer, served as an alternative approach to understanding the coping process and patients' attitudes towards psychosocial care. Two contrasting discourses were highlighted in this way: an individualistic discourse and a psychological discourse. Respondents employed various rhetorical strategies in order to ensure domination of the rational, individualistic, and coping 'I' over the emotional, psychologized mind. Taken together, these results suggest that less professionalised services, based largely on fellow patient support, should be central to a more consumer-friendly system of psychosocial care. An action research approach was recommended as a possible means of developing such a system of care.

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INTRODUCTION

Psychology, as a 'caring' discipline, has a long tradition both in academic and professional circles. The growing prevalence of chronic illnesses, such as cancer and more recently AIDS, has thus not surprisingly proved fertile career ground for many psychologists and associated professionals. Various methodological and clinical lenses are increasingly being focused on those who live for extended periods of time under painful and life-threatening circumstances. The experience of cancer has, in this regard, come under such scrutinous examination that many sturdy textbooks are now dedicated solely to the field of 'psycho-oncology' (Rowland & Holland, 1990) (in Europe the field is commonly referred to by the term; 'psychosocial oncology' - Greer, 1994). The ultimate aim of such work, of course, is to 'care'; to design and implement appropriate interventions which will, to some extent, improve the person with cancer's quality of life.

As with any social science, however, psychosocial oncology is hampered by various conceptual, methodological, and practical problems. Contrary to most other social sciences, however, the level of self-consciousness within the field, particularly with regard to the various problems it is experiencing, is astounding (Frank, 1992). At this level, the discipline is vulnerable to a comprehensive metatheoretical critique, a critique which has already altered the face of most social research (see Billig, 1987, 1991; Danziger, 1990; Gergen, 1985; Harre, 1983; Parker, 1989, 1992; Potter & Wetherell, 1987; Rose, 1990; Sampson, 1989, 1993). According to this 'post-modern' critique, the object of study (the cancer patient and his or her mental state and behaviour) is not a predetermined 'given', ready to be revealed to us by the methods of science. On the contrary, authors such as the above would argue that both the person with cancer, and the theoretical body describing him or her, are at least to some extent sociohistorically constituted through language and 'discourse'.

The human psychosocial response to cancer, in this regard, is not necessarily a fixed or stable ('natural') response emanating from individual subjects (determined by personality traits, stimulus-response learned behaviour, physiological response to stress, etc.), but is a response constructed by and through the various meaning systems contextualising the person with cancer's identity and self; meaning systems which are in turn embedded in the broader social structures of society. Psychosocial oncology, being part of such social structures, is therefore not simply reflecting a given state of affairs, but is actively playing a role (unself-consciously so) in the construction of the 'normal', 'adaptive', and sometimes even 'natural' response to cancer (Frank, 1991).

But so what, the psychosocial oncologist could argue. Of what use could a post-modern approach be to the actual life of the person with cancer? Of what use could it be in alleviating the suffering and distress people with cancer very evidently experience (even if aspects of it may be sociohistorically constructed) - especially since the traditional approach has been effective, first, in illustrating ('proving') that people with cancer do suffer psychologically (Holland, 1992), and secondly, that various forms of psychosocial care can, to an extent, alleviate such suffering (Anderson, 1992)?

Certainly the aim of a critical analysis should not be to 'disprove' the successes of mainstream psychosocial oncology. On the contrary, and this is an opportunity to contextualise the personal motivations behind this thesis, the overriding goal should still to 'care', to in some way attempt to improve the life with cancer. This author, probably like most workers and researchers in the field, has been personally captivated, both by the incredible psychological power of a cancer diagnosis, and also, perhaps more importantly so, by the tenacity and strength with which most sufferers bear this weight. What is this experience like, and how in God's name do you deal with it if it happens;- such is the type of question lying at the root of this thesis- and, ultimately, what psychosocial oncology is all about. Entire textbooks and periodicals are dedicated solely to the cancer experience, describing in perceptive detail how people react to the news of a diagnosis or the painful symptoms and treatment side effects. Scholars and clinicians gather from around the world to discuss these findings, and to discuss ways and means of helping people deal with such stressors in more effective ways. A noble pursuit, some might argue.

One contradiction stands out so notably, however, that it has led this author to wonder whether we really do understand what is going on. With all this effort being channelled into the understanding of the cancer experience, and the possible ways in which it could be made more bearable, most providers of psychosocial interventions have been left mystified by the exceptionally limited use of, and interest in, various forms of intervention among people with cancer (Knight, Wollert, Levy, Frame, & Padgett, 1980; Levy & Derby, 1992; Nelson, 1994; Taylor, Falke, Shoptaw, & Lichtman, 1986; Van Schalkwyk, 1995). If all the work, ultimately, is being done for people with cancer, why do the very beneficiaries not welcome the various services? This question has been left largely unanswered, probably partly because so few studies have focused on it. To this author, however, it seems impossible to ignore, because it questions the very legitimacy and validity of the discipline. What is the point of channelling scarce resources into unwanted services, and do we really understand what is going on if we cannot even convince the 'victims' themselves to make use of our services?

It is in this sense that a post-modern or constructionist approach could be useful, since it not only acknowledges, but also deals directly with the way a discipline can 'construct' its own subject matter (Danziger, 1990). Instead of gazing objectively upon the person with cancer, standing at a distance away from him or her, and sure in the knowledge that we are not in any way changing the 'nature' of that subject, we are offered the opportunity to analyse, in detail, the mutually constitutive interaction between subject and discipline. We can, in this sense, examine:

- how the character of the person with cancer we read about in journal articles and textbooks (the 'theoretical' subject) is at least partly *created* by the various theoretical and methodological approaches used to produce such research results;

- how the personal experience of the person with cancer (the person with cancer's subjectivity) is constructed - and continuously reconstructed - by broader social meaning systems, embedded in the person with cancer's own thought and talk (psychosocial theory, in other words, can participate in this construction of consciousness, instead of just being a reflection of it);
- how the person with cancer, in turn, comes to understand what psychosocial oncology and its services are all about (why the resistance?); and
- how the entire relationship is framed by diverse social meaning systems and social structures.

Using such an approach, it is possible to obtain a deeper (somewhat alternative) understanding of the cancer experience, one which could be of use to psychosocial oncology's worthwhile pursuits.

In chapters 1 and 2 of the thesis a brief review of some of the literature in psychosocial oncology will outline the nature of the problem. The case will be presented that people with cancer do quite obviously experience various forms of psychological distress, and that various forms of intervention do appear to ease such distress. This will set the stage for the perplexing findings that most people with cancer do not use such psychosocial interventions. Various explanations for this trend will be outlined, while illustrating their inadequacies. An empirical study in the form of a survey, presented in chapter 3, will enrich this discussion.

In chapter 4 an alternative approach to the problem will be presented, which will consist of an outline of, and argument for the social constructionist and discursive approaches. The argument will be put forward that the personal experience of people with cancer, and the theoretical bodies describing such people, are not simply unmediated reflections of a naturally occurring reality, but are at least partly a product of broader - and frequently contrasting - social categories embedded in language. The 'psychosocial consequences' of cancer, in other words, are not 'naturally' occurring 'human responses', but are *discursively constructed*, both by people with cancer themselves, and the researchers gazing upon them. For our purposes it is thus hypothesised that some tension or conflict exists in the way people with cancer understand their own experience and what role they expect the system of psychosocial care to play in this experience, resulting in a resistance toward psychosocial care. This hypothesis will be investigated in chapters 5 and 6 using discourse analytic principles. By means of focus groups and interviews, people with cancer themselves will be asked how they make sense of their situation and what their attitudes are toward various types of psychosocial care. An in-depth analysis will attempt to elucidate the various ways and means in which both the experience of cancer, and the various types of psychosocial care are constructed. Socio-linguistic roots of the potentially multiple and contrasting constructions will be discussed, as will the reflective and affirming role of psychosocial oncology in this process. More simply put, this analysis will attempt to understand how and why resistance toward psychosocial care develops. The thesis will come to a conclusion by drawing together the work done in previous chapters.

CHAPTER 1

THE PSYCHOSOCIAL IMPACT OF CANCER : A BRIEF REVIEW

That people with cancer generally experience a host of psychosocial problems is indisputable. Studies using psychiatric, psychological, and more social/anthropological frameworks have all documented various troublesome aspects of the cancer experience. Perhaps the most important point to be made, however, is that not all people with cancer experience the same set of psychosocial problems. Certainly all will to some extent experience feelings of sadness or anger, but not all will experience the disabling effects of major depression. According to this perspective, many psychosocial problems can be regarded as 'abnormal', 'unadaptive', or even 'pathological' responses. The underlying assumption and motivation behind most of psychosocial research in oncology, therefore, is that at least some of the problems can be countered by implementing various interventions.

The following review will examine the types of problems people with cancer experience from three perspectives. A psychiatric perspective is generally concerned with various forms of psychopathology; psychological problems deemed sufficiently abnormal and distressing to warrant the label 'pathology'. A psychological perspective is concerned with any form of emotional distress or behavioural problem, and a social perspective places the focus on interpersonal problems and broader socio-economic issues. The main thrust of this review will be to show that people with cancer quite obviously do experience various psychosocial problems, and that various forms of intervention could quite feasibly be indicated. As a result this review is decidedly brief. If more detail is required, the reader is referred to Rowland & Holland (1990).

1. PSYCHIATRIC PROBLEMS

According to the literature anywhere between 5-50% of people with cancer develop severe and persistent levels of depression and anxiety (Greenberg, 1992; Massie & Holland, 1990; Mermelstein & Lesko, 1992). More specific estimates put this figure at 23-40% (Greer, 1994). Such 'pathological' depression and anxiety can be distinguished from normal feelings of sadness and worry, since they last longer, are more severe, and frequently interfere with the treatment process (Barraclough, 1994). A significant prevalence of adjustment disorders, sexual dysfunction, and organic mental disorders among people with cancer has also been noted (Derogatis et al., 1983; Greer, 1994). Although the above estimates are certainly not disputed in the literature, the accurate assessment of psychiatric morbidity is hampered by the frequent overlap of symptomatology (is one "feeling slowed down" due to treatment side effects or depression?), and disagreement on appropriate assessment instruments (Snaith, 1993, Cella, Jacobsen, Kornblith, Lesko, & Marme, 1991).

2. PSYCHOLOGICAL PROBLEMS

Among the types of psychological problems people with cancer experience, feelings of uncertainty, negative feelings such as fear, shame, and loneliness, lack of perceived control over various aspects of one's life, feelings of helplessness, and reductions in self-esteem have been noted (Greer & Burgess, 1987; Pruyn & Van den Borne, 1987; Taylor, Falke, Shoptow, & Lichtman, 1986; Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). In recent years, an increasing number of quality of life studies have noted the particular psychosocial consequences experienced by people with various cancers. It has been found, for example, that women with breast cancer experience different concerns to men with lymphoma (Massie & Holland, 1991).

Several studies have furthermore shown that psychological morbidity may persist for many years after treatment has been completed (e.g. Cella et al., 1986). In this regard several authors have emphasised that the experience of cancer does not cease with the completion of treatment (Zampini, & Ostroff, 1993). With the advances in medical treatment of cancer, there exists now a growing population of cancer survivors who face the complex process of adjusting to life after cancer treatment. Numerous studies indicate that many such long-term survivors are dealing with a variety of problems ranging from emotional trauma and physical disabilities to employment and insurance discrimination (Monaco, 1992; Norman & Brandeis, 1992; Smith & Lesko, 1988; Tross & Holland, 1989; Zampini & Ostroff, 1993).

3. SOCIAL ISSUES

There is broad consensus among workers and researchers in psychosocial oncology that social support is probably the most powerful mediating factor influencing psychosocial adaptation to cancer. The person with cancer's relationship with his or her doctor, family, and friends has, in this regard, been the focus of numerous studies in psychosocial oncology (e.g. Bloom & Spiegel, 1984; Harrison, Maguire, Ibbotson, Macleod, & Hopwood, 1994; Massie & Holland, 1990; Spiegel, Bloom, & Gottheil, 1983). Such research has pretty consistently found that the 'perceived quality of support from others' (Harrison, Maguire, Ibbotson, Macleod, & Hopwood, 1994, p.173) predicts psychosocial adjustment. Although such work is marred by debates regarding appropriate definitions and operationalisations of social support, it is nevertheless clear that a *lack* of social support in many cases can be regarded as a serious psychosocial problem. Long-term cancer survivors, for example, frequently find that their main support sources used during treatment now expect the survivor to "get on with life like before" as it were (Bauman, Gervey, Siegel, 1992; Monaco, 1992). Simultaneously, however, such people are often still dealing with uncomfortable treatment side-effects, uncertainties regarding possible recurrence of disease, unresolved emotional difficulties, and social stigma, isolation, and discrimination.

It has also been noted by anthropologists and sociologists that people with cancer undergo a transformation in their social identity due to the extended adoption of the "cancer patient" role (Fagerhaugh, Strauss, Suczek, & Weiner, 1987), and the pervasive "cancer = death" stigma (Sontag, 1978; Stahly, 1992). Environmental conditions in hospital wards and interactional contexts of doctor-patient encounters can, as have been shown in several earlier studies, have a direct impact on a person with cancer's self-respect and physical and mental well-being (Gerhardt, 1990; Millman, 1977). Furthermore, discrimination of various forms has been experienced by people with cancer, most notably with regard to employment and insurance. In South Africa such socio-economic factors can be deemed of paramount importance due to the large proportion of people living close to poverty. Transport costs, medical costs, and more importantly, the inability to earn a living when ill (especially when supporting a family), can be greater burdens to people with cancer than the illness itself. In general, it can be argued therefore, that the experience of cancer is a thoroughly disempowering one (Monaco, 1992; Zampini & Ostroff, 1993), in that one's ability to function effectively at a physical, psychological, social, and economic level is severely threatened.

4. THE CAUSES OF PSYCHOLOGICAL MORBIDITY

The causes of psychological morbidity in cancer are reputed to lie in a combination of medical factors (site and clinical course of the disease, treatment side-effects, pain), psychological factors (adjustment to prior illness, history of previous psychopathology, intrapersonal coping ability, and developmental life-phase), and social factors (availability of social support from family, friends, and medical staff, socio-economic status) (Greenberg, 1992; Massie & Holland, 1990; Mermelstein & Lesko, 1992). It has been suggested that in South Africa low socio-economic status is an additional strong predictor of depression and anxiety (prevalence of depression in this population group has been observed to be as high as 50%) (Aucamp, 1994; Berard, Viljoen, & Boermeester, 1995.)

Much psychosocial research in this area, probably due to the obvious practical implications[1], has focused on the actual *process of 'psychological adaptation'* to cancer. The role of emotional support, coping ability, and perceptions of control as 'psychological factors affecting quality of life' (Greer, 1994) have received extensive attention in this regard. It is also here, however, that the theoretical depth and diversity within psychosocial oncology becomes apparent. For our purposes, it is thus also the area where the possible 'mixed messages', and various (and possibly contrasting) images of the person with cancer (constructions of the subject) will be examined (see chapter 6).

5. CONCLUSION

This chapter should have made clear that people with cancer do experience a large variety of psychosocial problems. Some of these problems, furthermore, are not temporary reactions or adjustment problems, but are enduring and disabling 'disorders' which can interfere significantly with the patient's quality of life and his or her medical treatment. For a more detailed and comprehensive overview of the psychosocial aspects and consequences of cancer, the reader is referred to Rowland & Holland (1990) and Barraclough (1994). For our purposes, however, the point is deemed sufficiently made that a large proportion of people with cancer could quite reasonably benefit from various forms of psychosocial intervention. In fact, it is currently estimated that at least 25% of patients and their families need some form of psychological support (Massie, Holland, & Straker, 1990). What such interventions look like, what they are meant to accomplish, and how successful they are - not only in improving the quality of life of people with cancer but also in attracting *participants* - will be turned to in the next chapter.

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[1] Besides possible avenues for intervention, Danziger (1990) has pointed out that a focus on 'individual differences' enables the production of more consistent and stable statistical data.

CHAPTER 2

PSYCHOLOGICAL INTERVENTIONS FOR PEOPLE WITH CANCER

1. A BRIEF HISTORICAL OVERVIEW

Ultimately, the aim of psychosocial oncology is to improve the psychosocial well-being of people with cancer through the implementation of psychosocial interventions. Traditionally, most cancer patients' psychosocial concerns were dealt with by oncology department social workers, and extreme cases of psycho-pathology (when picked up) were referred on to consultant psychiatrists. During the 1950's, cancer survivors in the United States complemented the available services by setting up several 'self-help' organisations (Gartner & Riesman, 1984; Massie, Holland, & Straker, 1990). These organisations arranged hospital visits whereby 'veteran' patients would talk to newly diagnosed patients, offering encouragement, support, and personal insights into 'coping'. Support groups for patients and family members were also set up, aiming to provide education and practical advice, mutual support, coping hints, and in some cases even political advocacy (in light of the social stigma of cancer). Reach-to-Recovery for breast cancer patients, and Candlelighters for children with cancer and their parents are examples of such patient-driven support organisations.

In recent years, however, several prominent cancer clinics have striven to exemplify the 'biopsychosocial model' (Holland, 1992) in their approach to patient care. Hospitals such as the Royal Marsden in London, and the Memorial Sloan-Kettering in New York, have introduced multidisciplinary teams, whereby psychologists, social workers, psychiatrists, and clergy are all included as part of the oncology team. Some of these progressive clinics also rely heavily on cancer survivor volunteers, who deliver a host of psychosocial services. Cancer patients at these clinics thus have access to education, crisis intervention, supportive and psychodynamic psychotherapy, group psychotherapy, 'veteran' visits, and mutual support groups. Intervention is, however, also aimed at family members (counselling, education), and oncology staff members (education regarding psychosocial issues, burn-out, etc.).

Although such ideal biopsychosocial clinics are rare, national cancer associations in various countries, have moved heavily towards the provision of psychosocial care, either by sponsoring self-help organisations, or by running various programs themselves.

2. AN OVERVIEW OF THE TYPES OF PSYCHOSOCIAL CARE

2.1. PSYCHOTHERAPY AND COUNSELLING

Although psychotherapy and counselling frequently refer to the same practice (e.g. 'talking cure'), it is possible to make some distinctions. According to Barraclough (1992), psychotherapy is more formalised and ambitious in that it aims to achieve lasting personality change in people with more long-standing psychopathology. Counselling, on the other hand, aims to help people deal more effectively with stressful life situations. As a result, counselling could be appropriate for a large number of cancer patients, including their families, whereas psychotherapy is only relevant for a minority (Barraclough, 1992).

2.1.1. COUNSELLING

Counselling for people with cancer is neither an established nor unified discipline. Although some workers might identify themselves as oncology counsellors, today most counselling in an oncology setting is still performed by a variety of different health care workers as just one of the many tasks they do. Doctors may, for example, 'counsel' their patients on how to live practically with treatment side effects, just as a social worker or nurse may 'counsel' newly diagnosed patients on what to expect during treatment. With few textbook guidelines or 'experts' available, counselling in oncology settings is thus still a rather informal practice. A description of some of the types of counselling available to people with cancer follows:

Nurse/ Social Worker counselling

Most oncology units employ a trained nurse-counsellor or social worker, who would make sure that patients understand the illness and treatment information correctly, help in the treatment decision making process, and provide practical advice and emotional support. More serious psychological problems would be referred on to psychiatrist or psychologist. According to Barraclough (1992) most patients welcome the help and support of a good nurse-counsellor.

Peer counselling

Some oncology units allow members of patient organisations to visit newly diagnosed patients, to offer practical advice, emotional support, and general encouragement. Many patients find such advice credible because it comes from a 'veteran'; a person who has been through a similar experience. Several commentators have noted, however, that unsupervised peer counselling can sometimes do more harm than good (Barraclough, 1992; Mastrovito, Moynihan, & Parsonnet, 1990). Care must be taken, according to such authors, that counselling is not forced upon patients.

Private counselling

Several national cancer associations employ private counsellors (frequently social workers), and in recent years there has been an increase in the number of private counsellors specialising in issues pertaining to cancer. Up to now, such practices are unregulated in the U.K. (Barraclough, 1992).

Counselling guidelines

Although counselling is infrequently regarded as a professional or theoretically based practice, some general 'how to' guidelines can be found in the literature. Barraclough (1992), for example, suggests that the counselling of cancer patients could aim to accomplish the following:

- Permit ventilation of feelings.
- Provide practical information about the illness, correct false assumptions and dispel unjustified fears.
- Encourage helpful ways of coping.
- Draw attention to any obvious 'maladaptive' strategies the patient is using (e.g. alcohol and drug abuse).
- Provide interest and support, and affirm the patient's self-worth.

2.1.2. PSYCHOTHERAPY

Compared to counselling, psychotherapy is far more theoretically based and is widely regarded as a 'professional' practice. Only full-time mental health professionals will tend to engage in this practice, and understandably so, their aims will be more ambitious than those of counselling. This does not imply, however, that the discipline is in any way unified. On the contrary, a continuing legacy of contrasting theoretical paradigms ensures varying practices and therapeutic goals. Separate discussions on the three dominant 'paradigms' follow:

Psychodynamic therapy

Classical long-term psycho-analysis is seldom deemed appropriate for cancer patients, but the briefer and more focused variants have been effectively applied [at the Tavistock clinic, London - Barraclough (1992); Judd (1994); Sonnenberg (1994).] A diagnosis of cancer and its associated problems can be regarded as a series of profound losses, and psychodynamic therapy would thus strive to enable the expression of 'grief' about these losses, so that such feelings can be 'worked through' (Barraclough, 1992). In psychodynamic terms, a diagnosis of cancer can be regarded as an emotional experience of such intensity that the mental apparatus could fail to 'contain' the chaotic psychic energy (Emmanuel, 1992). Psychodynamic therapy could function partly as a 'container' for such rampant emotion, and partly as a therapeutic 'frame' wherein the contextual factors (unresolved past experiences) causing and maintaining the dysfunctional mental apparatus could be dealt with. Some aims of psychodynamic therapy with cancer patients are as follows (Barraclough, 1992; Emmanuel, 1992):

- Linking past and present. Exploring the parallels between a previous life crisis and the present cancer diagnosis.
- Interpreting mental defense mechanisms. A patient may project his unacknowledged anger and frustration onto his wife in the form of irritability. A patient turning to his or her parents for support instead of his or her spouse may be regressing under the stress of the illness.
- Interpreting the transference and countertransference. The feelings aroused in the therapist may be useful information pertaining to the unresolved feelings ('nameless dread') the patient projects outward.
- Identifying resistance. What is the patient avoiding to discuss? (more unresolved feelings and nameless dread).
- Interpreting dreams. More clues pointing toward the characteristics of the unresolved issues.

Behaviour therapy

Behaviour therapy resists the temptation to interpret a patient's symptoms in terms of its possible origins, and uses a practical and structural approach to discourage undesirable behaviours and substitute them with more appropriate ones (Barraclough, 1992). Following the assumption that all behaviour is learnt, the behaviour therapist would aim to 'unlearn' unwanted behaviours using the principles of classical and operant conditioning. Procedures such as desensitisation and distraction (relaxation therapy, hypnosis, etc.) have been successfully applied to such problems as anticipatory nausea (before chemotherapy) and pain which gets worse in certain emotional situations.

Cognitive therapy

Forming a meeting ground between behaviour therapy and psychodynamic therapy, cognitive therapy has been successfully applied to cancer patients at the Royal Marsden Hospital in London by Moorey & Greer (1989). According to this theory, emotional problems are caused and maintained by maladaptive beliefs and thinking patterns. The meaning and emotional threat of cancer depends, in this regard, on the patient's 'cognitive schema' which is derived from individual past experience (Barraclough, 1992; Moorey, 1994). By over-generalising rigid black-and-white beliefs (e.g. you always die in agony with cancer), the patient may develop inflexible and unadaptive coping skills. Therapy would encourage the patient to identify his or her 'automatic thoughts', so that they may be evaluated more logically, and contrasted with alternative attitudes and behaviours which allow the patient a greater sense of control over their situation. Specific aims and techniques are as follows (Barraclough, 1992):

- Identify, record and challenge negative automatic beliefs.
- Rehearse impending stressful events and ways of handling these (visualisation and role play).

- Plan and carry out practical activities which instil a sense of mastery, control, and pleasure.
- Express feelings openly to one's partner.
- Raise self-esteem by identifying and fostering personal strengths.

2.2. PATIENT SUPPORT GROUPS

It is a well-documented fact that the availability of social support is an exceptionally important factor influencing psychosocial adaptation to cancer. As a result, the concept of patient 'support groups' has received considerable attention in psychosocial oncology circles. Two distinct types of support groups can be identified: self-help groups and support groups facilitated by a trained professional.

2.2.1. SELF-HELP SUPPORT GROUPS

Although there is traditionally caution among certain sectors of the medical community in accepting the concept of fellow patient support, this hesitation has been diminishing (Ettinger & Heiney, 1993; Rowland & Holland, 1990; Mastrovito, Moynihan, & Parsonnet, 1989), and is reflected in the popularity of mutual support networks in the United States (Ettinger & Heiney, 1993; Monaco, 1993) and Europe (Katz, 1984; Pruyn & Van den Borne, 1987; Stevens & Matthijs, 1994).

The essential characteristic of self-help groups is that the help and support is provided and facilitated by fellow patients. Groups are facilitated by patients and ex-patients, personal meetings are organised between patients currently going through treatment and long-term survivors, and ex-patients and current patients are actively involved in the design, management, and implementation of support networks. Several commentators (Gartner & Riessman, 1984; Jacobs & Goodman, 1989; Mastrovito, Moynihan, & Parsonnet, 1989) have noted that the primary reliance on collective, experiential knowledge creates a process quite distinct from any professionally run psychotherapeutic intervention. Cancer patients often have difficulty disclosing their distressed feelings, which in turn can lead to isolation and alienation. Patients might not feel understood by their friends or family, or might wish to protect them with a facade of happiness. The fellow patient group, however, through the provision of experiential empathy (Mastrovito, Moynihan, & Parsonnet, 1989) (or the 'sense of symmetry' [Jacobs & Goodman, 1989]), assists the new member in communicating his or her fears and anxieties. In this way the patient is able to obtain 'credible' information from people who have been through it, thus reducing feelings of uncertainty (Pruyn & Van den Borne, 1987). Emotional support and encouragement from people who 'really' understand is provided, thus reducing feelings of isolation, and linked to this, the patient is able to evaluate his or her own feelings by comparing them with others (thus 'normalising' them) (Pruyn & Van den Borne, 1987). Isolation and stigmatisation is transformed into acceptance, understanding, and empowering 'normality' (Jacobs & Goodman, 1989).

Self-help groups have come under criticism, however, because some participants may not benefit from such encounters, in fact they may experience an increase in their anxiety levels (Dunkel-Schetter, 1984; Hitch, Fielding, & Llewelyn, 1994). Necessary defences may be destroyed, fear of recurrence or dying may be aggravated, group leadership may be ineffective, and the imposition of group norms may result in power rivalry and exclusionary tactics. Although some authors have emphasised the gravity of these problems, in effect arguing for more high-policy regulation of self-help groups (Hitch, Fielding, & Llewelyn, 1994), the point these authors seem to miss is that self-help groups do not (or at least should not) claim to be 'therapeutic interventions', and thus do not fall under the categorising lens determining what counts as 'therapeutic' and what doesn't. A self-help group is a gathering of people, and like any gathering may not always be pleasant, constructive, or therapeutic, in fact, it may in instances be simply 'play' (instead of 'work') but it certainly need not apologise for that. Self-help groups, according to its proponents, would not have the power to cure a nervous breakdown, but neither would it have the power to cause it (at least no more than ordinary meaningful interaction could).

2.2.2. PROFESSIONALLY RUN SUPPORT GROUPS

Several institutions such as cancer associations, oncology units, and hospices offer professionally run support groups. These type of groups also depend on the concept of fellow patient support described above, but do differ to self-help groups in various ways (Hitch, Fielding, & Llewelyn, 1994; Toro et al. 1988). In order to avoid the types of problems (ineffective or harmful processes) associated with self-help groups, many health care institutions employ professional group facilitators (e.g. social workers, psychologists, psychiatrists). Professionally run groups therefore generally have explicit aims, such as enabling terminal patients come to terms with anxieties and anger. The approach also tends to be more formal and psychologically directed. Toro et al. (1988) found, for example, that the facilitator and participants in professionally run groups showed fewer agreements and self-disclosures, and less small talk and information giving. The implication is suggested therefore, that the inclusion of a professional destroys the very core ideology of self-help groups (i.e. democratic participation, self-governance, and informal 'grass-roots' support). Although not quite group therapy, the professionally run group thus nevertheless falls under the auspices of a psychological or 'therapeutic' framework, which determines what is supposed to happen in such a group. (A professionally run group very certainly is 'work', not 'play'.)

In recent years, a more educationally orientated form of support group has been offered by various health care organisations. Such programs have tended to focus on specific aspects of the cancer experience and the coping skills needed to deal effectively with such problems. Although such educational interventions are rooted primarily in frameworks which emphasise the important role of adaptive coping strategies (i.e. one can learn how to cope effectively), additional support for such interventions has come from studies which suggest that males might find such interventions more appealing (as opposed to 'emotional' interventions) (Taylor, Falke, Shoptaw, and Lichtman, 1986).

3. THE EFFECTIVENESS OF PSYCHOSOCIAL INTERVENTIONS

A fair amount of research has attempted to test the efficacy of various psychosocial interventions for people with cancer, but like most psychotherapy research, has received substantial methodological critique. Nevertheless, several recent reviewers (Anderson, 1992; Massie, Holland, & Straker, 1990; Meyer & Mark, 1995; Trijsberg, Van Knippenberg, & Rijpman, 1992) supported the value of a range of psychosocial interventions to provide emotional support in people with cancer. Such support, provided by mental health professionals or trained cancer survivors, in either group or individual setting, appears to be effective in relieving emotional distress, and improving 'coping ability'. Such results are, off course, by no means equivocal. Reele (1994), for example, found that neither counselling nor a coping skills course had any effect on participants' quality of life, and Hitch, Fielding, & Llewelyn (1994) expressed caution in affirming the supposed benefits of self-help groups.

Although the efficacy of various psychosocial interventions is generally accepted, more 'socially' orientated commentators have levelled some powerful criticism at psychosocial care (to a degree perhaps reflecting the general discontent with psychotherapy in academic circles- [e.g. Dryden & Feltham, 1992]). Before moving on to this critique, however, a brief review of the psychosocial services available to people with cancer in the Cape Town region is required.

4. THE SITUATION IN THE CAPE TOWN REGION

Most people with cancer in the Cape Town region are treated at the Radiotherapy department in Groote Schuur Hospital. In terms of psychosocial care, people with cancer can find such services at Groote Schuur Hospital, the Cancer Association of South Africa (CANSA) (more specifically the Cancer Care and Resource Centre), St. Lukes Hospice, and the private sector. A more detailed look at the various types of care follows.

1. Psychiatric care

Extreme cases of psychological morbidity and other psychopathology (when picked up by medical staff) are referred on to one consultant psychiatrist attached to Groote Schuur Hospital. This psychiatrist runs a full-time adolescent centre outside Groote Schuur Hospital and thus has little time available to see patients. Since there is no routine screening for psychological morbidity, and since the oncologists have very limited time available per patient, it is feared that the vast majority of cases are left undiagnosed and untreated (especially since an ongoing study [Berard, Viljoen, & Boermeester 1994] put the prevalence of major depression among cancer patients at 10%, and Aucamp [1994] found that 40-50% of her sample of socio-economically disadvantaged patients scored depressed on various depression rating scales).

2. Social work

One social worker is attached to each oncology unit and two are employed by CANSA head office. Some of the regional CANSA branches also employ social workers. These social workers help patients obtain disability grants, and offer information and counselling pertaining to almost any feasible 'psychosocial issue' (ranging from breast prosthesis to emotional issues in the family).

3. Psychotherapy

A number of private psychotherapists specialise in psychotherapy with cancer patients. None are attached to hospital oncology departments however, and only one is employed on a contract basis by the South African Cancer Association (CANSA) (Cape Town) in the Cancer Care and Resource Centre.

4. Counselling

A number of private social workers and qualified counsellors offer counselling to cancer patients. Only one social worker is attached to each oncology unit, and two are employed by CANSA for their head office. One Health Psychology intern (who is a trained counsellor) has recently been attached to the Department of Oncology on a part-time basis. The Philani clinic in Guguletu (a CANSA satellite) offers counselling to patients.

5. Coping skills courses

CANSA (the Cancer Care and Resource Centre) runs an annual "I Can Cope" course (imported from the United States) at its Mowbray head office. This is an eleven week course whereby participants attend weekly evening sessions. Each session deals with a different aspect of the cancer experience. 'Experts' are invited to speak on relevant topics (e.g. chemotherapy, sexuality), after which group discussion takes place. It remains largely unpopular (personal communication, CANSA), and has recently been substantially shortened in the hope of making it practically more feasible for people with cancer to attend.

6. Support groups

At the close of the annual "I can cope" course, participants are invited to continue meeting as a support group. These support groups are facilitated by a social worker. The Philani clinic also runs a support group.

Reach-for-Recovery, an international mutual support organisation for breast cancer patients, runs support groups.

An independent social worker occasionally runs support groups for breast cancer patients in the oncology ward at Groote Schuur.

7. Self-help groups

Reach-for-Recovery, although not essentially a self-help group (since they fall under the auspices of CANSA), organise 'veteran' visits to nearly all newly diagnosed breast cancer patients at Groote Schuur Hospital. Regular meetings and support groups are also held.

8. Informal 'support groups' and 'counselling'

Although not formally identified as 'support groups', both St Lukes Hospice and various CANSA satellites (e.g. Eikenhof Interim Home) have day-care centres where patients are able to seek medical information, access social work services, and meet other patients. Such 'groups' are informal gatherings where patients socialise with each other (while knitting for example). Staff members who run these centres are of the opinion that such informal 'work' is exceptionally popular and effective (personal communication, Nelson, 1994; personal communication, Tanchel, 1995).

5. CRITIQUE OF PSYCHOSOCIAL INTERVENTIONS FOR PEOPLE WITH CANCER

As discussed, psychological interventions for cancer patients have been shown to be relatively effective in enhancing patients' quality of life (Andersen, 1992; Hitch, Fielding, & Llewelyn, 1994). Nevertheless, they have also come under serious criticism from more 'socially' orientated commentators (Chesler, 1991, 1993; Cincotta, 1993; Gartner & Riesman, 1984; Frank, 1992.) Some of these issues - discussed below - also have particular relevance to the South African situation.

Most research and effort to provide psychosocial care still proceeds from a 'pathology' model rather than a 'health' model (Chesler, 1993; Gartner & Riesman, 1984). Most people and their families afflicted by cancer are reasonably healthy in psychosocial terms; they are generally 'normal' people experiencing a major and prolonged trauma. Health professionals however (particularly in the United States and Europe), tend to 'professionalize' life crises, and subsequently design specialised 'treatment plans' which aim to 'cure' the aversive condition. Such an approach, according to critics, not only leads to poor diagnostic assumptions and assessment failures, but also often sends a message to patients and family members that is disempowering, frightening, and may well create the very problems we seek to avoid (Chesler, 1993; see Lazarus, 1983). *Supportive* care of various kinds, which seeks to *prevent* pathology, and which is presented in ways that **respect** the health and dignity of patient and family, is argued for by these authors.

Psychosocial care is too often not provided on a holistic and integrated basis (Chesler, 1993). Cancer as a biopsychosocial "illness" (as against "diseased tissue") (Kleinman, 1988) does not exist within an encapsulated individual, but exists and is experienced primarily as a social phenomenon (see Berger, 1990). Psychosocial concerns tend to be conceptualised and treated, however, without attending to their enmeshment in a wider system of care-givers, family, and community. There is also a general lack of treatment co-ordination and follow-up. In a similar line, **psychosocial services are seldom provided over time and designed to work with a patient and family through the varied stages of medical treatment and psychosocial progress** (Chesler, 1993). An integrated, comprehensive, and well-organised psychosocial care network dealing with all phases of the illness and treatment, involving patient, family, and even wider community, is therefore argued for by these authors.

Psychosocial programs may be responsive to patient and family concerns, but they seldom seek to empower patients and family members (Chesler, 1993, Gartner & Riesman, 1984). Seldom are patients and families involved as partners in the design and guidance or management of these programs, and there is often substantial resistance on the part of medical and psychosocial practitioners to the notion of assertive and empowered patients and families.

Not only is most psychosocial research and intervention not sensitive to cultural and economic class factors, and generally unreflective of the value-systems it implicitly assumes and thus prescribes (Aaronson et al., 1990; Cincotta, 1993), **it also is simply not available to a large proportion of patients and their families.** The ideal psychosocial care network should therefore extend well into disadvantaged communities, and be culturally sensitive and non-prescriptive.

It could be argued that the available psychosocial care facilities do not address the most important concerns facing cancer patients in South Africa. There is some evidence to suggest that the factors associated with high psychological morbidity are not of a psychological nature, but of a socio-economic nature (Aucamp, 1994; Berard, Viljoen, & Boermeester, 1994.) As a result, services which focus on psychological concerns are perhaps largely inappropriate for most cancer patients in South Africa.

In South Africa, the psychosocial assessment and treatment of cancer patients has never been a cost-effective option. Considering current and future health budgets, the hiring of numerous extra mental health professionals is totally unfeasible. As a result, if a potential care system is to have any chance of progressing beyond the conceptual stage, it would need to prove its cost-effectiveness.

Most of the above issues are important in their own right but can also be regarded as symptoms of a broader issue regarding health care policy. **The medical and psychosocial treatment of cancer patients in South Africa is still rooted in a health care system dominated by tertiary care.** Most psychosocial care is still enmeshed within a bureaucratic institution of professionals, which finds itself largely incapable of dealing cost-effectively with the scope and *diversity* of problems patients in South Africa experience. It can be argued that a health care system based on large central institutions and tertiary care simply is not suited to dealing with ever increasing numbers of (diverse) people living with chronic illness, and the psychosocial problems that inevitably accompany chronic illness (Gartner & Riesman, 1984; Gerhardt, 1990; Strauss, 1990).

More emphasis on primary care and community networking is therefore recommended by such authors, as a more efficient and effective way of dealing with current and future health care needs.

Psychosocial oncology, as a discipline, has in recent years also come under criticism for having lost awareness of itself as a moral discourse, in presenting claims about the nature of and proper response to suffering (Frank, 1992). No attention is paid to the fact that the experience of suffering is not simply a natural 'psychological response to cancer,' but is an experience partly constructed through everyday *and scientific* discourses as to what is the proper or normal response to cancer. Not only is there a serious lack of self-consciousness present in psychosocial oncology as regards the validity of their knowledge claims and the role such claims play in shaping people's reactions to cancer, but also no account is taken of possible marginalizing and disempowering effects on those people who now become 'patients' who use 'maladaptive coping strategies' or 'present with psychopathological reactions' and are thus in need of 'treatment' (cf. Brownell, 1991; Lazarus, 1983).

The distinctive power of the above critique lies not in their empirical weight but in their conceptual critique. Hardly any attempt is made by the above authors to check empirically whether psychosocial interventions 'work' or not. On the contrary, the main points of argument question the validity of the conceptual framework on which most of the system is based (i.e. the very criteria determining the meaning of an intervention which 'works'). Far from being scientific, neutral, or objective, the psychosocial framework, according to these authors, is decidedly individualistic in approach, and as a result is forced to conceptualise the problem, and the prescription of how to correct it, in a very specific manner. The problem in this regard, is a problem 'inside the patient's head'; it is a psychological problem which can be made sense of using theoretical frameworks which describe the mechanics of the universal psyche. As a result, a psychological intervention is prescribed which targets these mechanics inside the psyche. From a social perspective, the result is a system which is insensitive to the broader social dynamics constructing the ‘nature’ of the problem. Although certainly powerful, the above criticisms do miss a crucial point; the person with cancer’s attitudes and reactions toward the whole psychosocial system (and associated debates). If the cancer experience is sociohistorically contextualised (i.e. if very few universal statements can be made about it) then surely the best place to start over would be with the views and wishes of the people with cancer themselves. Do the intended recipients of psychosocial care take issue with the current state of affairs, and if they do, why?

6. THE UTILISATION OF PSYCHOSOCIAL SERVICES

Studies in the United States and Europe have noted that many psychosocial care services have very limited appeal to cancer patients (De Bocanegra, 1992; Taylor, Falke, Shoptaw, & Lichtman, 1986; Tishelman & Sachs, 1992; Worden & Weisman, 1984), and those that do use them have specifically identified demographic and psychosocial characteristics. Knight, Wollert, Levy, Frame, & Padgett (1980), and Taylor, Falke, Shoptaw, & Lichtman (1986) found that people with cancer who join support groups tended to be younger, white, middle-class females who, compared to non-attendees, used more social support resources of all kinds (see Levy & Derby [1992] for a perspective on bereavement support groups). Bauman, Gervey, & Siegel (1992), similarly, found that support group attendees tended to be college educated, younger, unmarried ‘joiners’ of other voluntary organisations, and help seekers who had consulted mental health professionals before. Slevin et al. (1988), evaluating the British telephone cancer information service (BACUP), found that males of lower socio-economic class hardly used the service. It should be emphasised at this point however, that the above noted demographic categories refer only to crude generalisations - resistance is high across the board.

In South Africa, clinicians have similarly noted the rather severe lack of interest in the ‘I Can Cope’ course and related support groups offered by CANSA’s Care and Resource Centre (personal communication, CANSA, 1994). Utilisation of CANSA’s Cancer Care and Resource Centre (which hosts the ‘I can cope’ course, counselling, stress management, support groups) has, in fact, been so low that the centre is coming under pressure to justify its cost-effectiveness (personal communication, CANSA, 1995). A social worker at Groote Schuur Radiotherapy department has also repeatedly emphasised the difficulty she is encountering in persuading psychologically distressed patients to seek out formal psychological help. Such resistance among males, and people of lower socio-economic class is not even limited to psychosocial issues. In the United States, for example, Kerner (1994) observed that people of lower socio-economic class were even exceptionally resistant to seeking medical help (resulting at least partly in the high prevalence of advanced disease among these populations). In South Africa, clinicians have observed similar trends (Albrechts, 1994).

Various explanations for the above trends have been proposed. For one, it has been noted that the above results reflect the more general finding that traditional mental health services appeal only to a specific segment of society, namely: white middle-class females (Gurin, Veroff, & Feld, 1979; Taylor, Falke, Shoptaw, & Lichtman, 1986). In other words, it appears that a large segment of society is already predisposed to avoiding psychosocial services aimed at cancer patients (i.e. it could have little to do with the fact that the services are aimed at cancer patients). The question nevertheless remains as to why such people do not use psychosocial services.

One could argue that non-users experience fewer psychosocial problems than users of psychosocial services (Hitch, Fielding, & Llewelyn, 1994). Berard, Viljoen, Boermeester, & Johnson (1995), in an on-going study with cancer patients at Groote Schuur Hospital, have, however, provisionally found no significant difference in the prevalence of depressive symptomatology between male and female cancer patients, but did find that the prevalence was significantly higher among patients of lower socio-economic class (the very group who supposedly do not use psychosocial services). It is not a foregone conclusion, therefore, that non-users experience fewer psychosocial problems, although this would need to be investigated more directly.

It has also been proposed that non-users feel psychosocial services do not address their needs. Such people could feel that they receive sufficient support from family and friends (de Bocanegra, 1992; Knight, Wollert, Levy, Frame, & Padgett, 1980; Taylor, Falke, Shoptaw, & Lichtman, 1986), and thus do not need 'extra' support. Pistrang & Barker (1992) found that a sample of breast cancer patients tended to identify informal helpers (partners, close relatives and friends) rather than formal helpers, as the most important person to whom they confided. Taylor, Falke, Shoptaw, & Lichtman (1986) have also noted that people with cancer identify their close family and friends as the most important sources of support. Significantly, the medical caregivers are also frequently identified as equally important sources of support (Dunkel-Schetter, 1984; Taylor, Falke, Shoptaw, & Lichtman,1986). Barraclough (1994) argued that such positive appraisals of the medical care giver are due to a type of 'transference' effect whereby the patient projects everything 'good' onto the doctor. Tishelman & Sachs (1994), similarly, but more cynically so, argued that the patient needs to 'construct' an almost mythologically perfect doctor in order to maintain some semblance of order in a life descending into disorder. In a general sense therefore, it appears that people with cancer tend to look for emotional support from their family, close friends, and sometimes their doctor. To a degree, this explains why interest in other forms of social support is low. The question can nevertheless still be asked as to why people prefer support from those three sources, avoiding more formalised sources? Furthermore, what if the person with cancer is unable to satisfy his or her social support needs through family, friends, or doctor? Questioning whether users of support groups might have unsatisfied social support needs, Taylor, Falke, Shoptaw, & Lichtman (1986) came to the striking conclusion that users of support groups were ***more likely*** to have satisfactory communication with family and friends, than non-users. The relationship between use of psychosocial services and social support needs is therefore certainly not clear.

The above findings do point toward the suggestion that people could be seeking out different people for different types of support. Rose (1990), in this regard, found that cancer patients preferred the support from family and friends for dealing with affective (emotional) reactions to stressful events. Health professionals, however, were preferred for 'open communication' and 'clarification'. Intimate matters, in other words, are the domain of close family and friends, and information is the domain of experts. Taylor, Buunk, & Aspinwall (1990), similarly, showed how cancer patients appear to seek out different people for information needs (experts), emotional needs (family, close friends), and self-appraisal needs (fellow patients). It is in this regard that Falke & Taylor (1983), Jacobs, Ross, Walker & Stockdale (1983), and Taylor, Falke, Shoptaw, & Lichtman (1986) suggested that a different type of service, one more orientated towards education, information, and family participation could appeal more to traditional non-users of psychosocial services (CANSA's 'I Can Cope' course is an example of such an approach - an unsuccessful one).

The above discussion does not, unfortunately, explain why it is that some people prefer not to deal with 'experts' regarding emotional matters, and why those people tend to be males and people of lower socio-economic class (most distressed middle class females also appear to avoid psychosocial care). In this regard it has frequently been suggested that non-users have more difficulties acknowledging that they might have psychosocial problems, and thus resist seeking help (Taylor, Falke, Shoptaw, & Lichtman, 1986). Such resistance has been conceptualised in various ways, ranging from 'denial' by more psychodynamically orientated commentators (Barraclough, 1992) to less technical descriptions such as 'male macho' attitudes. Either way, however, the implicit assumption is that somehow such people are not 'in touch' with their emotions. The emotional state, in other words, is a given - it is conceptualised as 'psychological distress', 'depression', or 'mental illness' - but the actual victim is not aware of his or her 'distressed' emotional state. He or she has 'covered it up', 'masked' it, or 'repressed' it. One can ask the question again, however, why so many people find the need to 'mask' their distress so powerful. Mastrovito, Moynihan, & Parsonnet (1989), quoting a patients' own account, suggest that the very intensity of the distress may preclude the sufferer from seeking help. "The fear is so engulfing it precludes the ability to call for help" (p.502). Again one can ask, however, why there exists this fear toward psychosocial help (a drowning person, though frightened, will surely not hesitate to cry for help?).

It has also been suggested that non-users of psychosocial care are practically not able to utilise psychosocial services due to time, cost, and transport constraints. Although in the United States, Bauman, Gervey, & Siegel (1992) found that geographic distance from the service did not distinguish users of support groups from non-users, it remains to be seen whether such practical difficulties are not relevant in the South African context.

As discussed earlier, Chesler (1991, 1993) has made the further suggestion that most forms of psychosocial care are based on a pathology model and are over-professionalised. Such services, he argues, are potentially intimidating, disempowering, and stigmatised. Some tentative support for the relevance of this argument to the Cape Town situation is available. Although staff at the Cancer Care and Resource Centre are frustrated by the poor utilisation of their professional services (counselling, 'I can Cope' course, support groups, etc.), staff members at St Lukes and some of the CANSA day-care centres are highly enthusiastic regarding the apparent popularity and success of informal 'support groups' (where people eat, knit, chat, and inadvertedly 'support') (Nelson, 1994; Tanchel, 1995).

The above discussion provided more questions than answers, and illustrated the complexity of the situation. Commentators have attempted to link the use of psychosocial support to social support needs, practical factors, degree of psychosocial distress, and defense mechanisms. In nearly all cases, however, the result is a chaotic web of contrasting, and sometimes somewhat absurd finding. What can be said, however, is that there appears to be a widespread *resistance* toward psychosocial care among the intended recipients. More tentatively, it can also be stated that such resistance is more pronounced among males and people of lower socio-economic class, and that people prefer the support of friends, family, and doctor (as opposed to mental health professionals).

7. CONCLUSION

A concise description of the cancer experience, as mirrored by psychosocial studies, has been provided. It has been made clear that people with cancer do experience an array of psychosocial problems, and that in many cases various forms of psychosocial care are indicated in order to improve quality of life. The various types of psychosocial care and the way they propose to deal with psychosocial problems have also been described, as have their effectiveness. At that level it is difficult to diagnose anything fundamentally problematic; there are some problems and several proven interventions are available to counter such problems.

A large proportion of the intended recipients, however, appear to resist such well-intentioned, and what may seem straightforward, attempts at 'caring'. Besides the frustration it causes among mental health professionals, it is argued that such problems put into question the very legitimacy of psychosocial oncology. Can the discipline claim to understand what is going on if it cannot even convince the 'victims' themselves to use what are clearly useful services? Furthermore, why waste precious resources on unwanted services, in particular if such funds could be used to combat the root problem- i.e. cancer?

The situation in South Africa has, however, not been systematically examined. Although one need only talk to mental professionals at Groote Schuur Hospital and CANSA to suspect that the situation is no different to that in the United States and Europe (if not worse), some research is required to justify further academic discussion. As a result a brief and straightforward survey has been conducted to assess the interest in psychosocial services among people with cancer.

CHAPTER 3

RESISTANCE TOWARD PSYCHOSOCIAL INTERVENTIONS: A SURVEY

1. INTRODUCTION

As discussed earlier, little is known about the utilisation of, and interest in psychosocial interventions, among people with cancer in the Cape Town region. Based on discussions with staff at Groote Schuur Hospital and the Cancer Association (personal communications, CANSA, 1994; Van Schalkwyk, 1995), it is evident that the utilisation of psychosocial services is exceptionally low. Very few people with cancer attend the 'I can cope' course and just as few attend support groups. Utilisation of the CANSA's Cancer Care and Resource Centre (which hosts the 'I can cope' course, counselling, stress management, support groups) has, in fact, been so low that it is coming under increasing pressure to justify its cost-effectiveness. The social worker at the breast clinic, similarly, has found that psychologically distressed people with cancer frequently reject offers for professional help.

By examining the literature (see chapter 2), various possible explanations for these apparent trends can be proposed. For one, it is possible that people with cancer would actually like to utilise psychosocial services but cannot do so for various practical reasons (e.g. transport, time constraints, cost, etc.). Secondly, the majority of people with cancer could regard their family, friends, and doctor as the most important sources of social support, and thus feel they are not in need of additional emotional support. Thirdly, it could be that people with cancer in the Cape do not experience the types of psychological distress prevalent in Europe and the United States, with the result that such people feel no psychosocial intervention is required. The latter two points allude to the overriding possibility that different people, seek out different types of help and support, from a variety of different sources. Lastly, it could be that people with cancer in the Cape Town region only reject certain types of intervention. Chesler (1991, 1993) has suggested, for example, that most psychosocial care is over-professionalised and is thus disempowering, intimidating, and stigmatised. It is possible therefore, that only the more professionalised forms of intervention (e.g. psychiatry, psychology) are rejected, and that more interest could exist in fellow patient support orientated services.

In order to examine some of these issues a short questionnaire survey was performed. Logistically, a full-scale survey of a representative sample of people with cancer was out of reach. Instead, a short questionnaire was added to an assessment battery which formed part of a separate study (Berard, Viljoen, Boermeester, & Johnson, 1995). In this way a convenience sample of 84 people with cancer completed the survey questionnaire. In light of the previous discussion, the aim of the survey was to throw light on the following questions:

2. AIMS

1. *What percentage of respondents have utilised psychosocial interventions, and if so what type of interventions did they utilise?*
2. *What percentage of respondents express an interest in various interventions?*

The above aims are the crux of this survey since this thesis is concerned primarily with supposed resistance toward psychosocial services. This supposed resistance needs to be assessed empirically. Furthermore, it needs to be determined whether people with cancer do not use the services because they cannot do so practically, or because they do not <u>want</u> to utilise them.

3. *Are there any demographic differences between people who express a desire to utilise services, and those who do not express such a desire?*

In the previous discussions in chapter 2, it was highlighted that users of psychosocial care tended to be predominantly white, middle class females (Gurin, Veroff, & Feld, 1979;

Taylor, Falke, Shoptaw, & Lichtman, 1986). Due to the nature of our convenience sample, it was impossible to fully investigate the demographic characteristics of psychosocial care users as opposed to non-users. Within these sampling constraints, however, it was still possible to examine the role of 'race', earning status, age, and various illness factors.

4. *Do non-users and respondents showing no interest in interventions experience less distress, and to what extent do distressed respondents use and show an interest in interventions?*

The very foundation of psychosocial oncology and any system of psychosocial care rests on the tested assumption that a proportion of people with cancer experience various forms of psychosocial problems, and that such people in particular need various forms of intervention. A question to be posed therefore, is to what extent those people with cancer who present with 'psychological morbidity', seek out or show an interest in psychosocial care.

5. *Who do respondents identify as their main sources of social support?*
6. *Do non-users and respondents showing no interest in interventions report higher levels of received social support from family, friends, and doctor, compared to users and people showing an interest in interventions?*

In chapter 2 it was suggested that people do not use, or do not show an interest in psychosocial care since they seek out family, friends, and to some extent their doctor, for emotional support (de Bocanegra, 1992; Knight, Wollert, Levy, Frame, & Padgett, 1980; Rose, 1990; Taylor, Falke, Shoptaw, & Lichtman, 1986). Is this the case here in Cape Town, and what about people who are of the opinion that they do *not* receive sufficient emotional support from family, friends, and doctor? Would such people be more likely to seek out the services of mental health professionals or other related services?

7. *Are some types of psychosocial care preferred over others by respondents? What are respondents' attitudes toward fellow patient support?*

It has been suggested that people seek out different types of services or sources of support for different functions. It is possible, for example, that more educationally orientated services could appeal more to people who seek out emotional support from family and friends (Falke & Taylor, 1983; Jacobs, Ross, Walker & Stockdale, 1983; and Taylor, Falke, Shoptaw, & Lichtman, 1986). Several commentators (Chesler, 1991, 1993; Cincotta, 1993; Gartner & Riesman, 1984) have also suggested that people with cancer might show more interest in fellow patient support (as opposed to counselling or psychotherapy) since it is less professionalised and more credible ('all in the same boat'). This thesis will be tentatively explored.

8. *What are some of the reasons people give for not using interventions?*

So far various decidedly rational and theoretical explanations have been explored. A picture has been presented, in other words, of a person with cancer who evaluates his or her needs in a rational manner (at least rational in psychological understandings), and thus comes to the logical conclusion that he or she does not require psychosocial intervention. It is probably wise, however, to ask people with cancer themselves why they do, or do not use psychosocial services. It could be that their notion of rational decision making is decidedly different.

3. THE QUESTIONNAIRE

A questionnaire was developed based on the above stated research aims. By participating in a separate study, this researcher has had the opportunity to engage in informal discussion with a wide variety of people with cancer attending the Groote Schuur out-patient clinic (Berard, Viljoen, Boermeester, & Johnson, 1995). Such discussions informed the exact wording of the questionnaire. A full version of the questionnaire can be found in the appendix. What follows is a run down of the various questions, what they were supposed to be asking, and how they were developed.

In the first place, respondents were asked whether they had ever used, or would ever have liked to use (including at time of interview) the following types of psychosocial intervention:

- Consultation with a psychiatrist.
- Individual counselling or psychotherapy with a counsellor or psychologist.
- Consultation with the department social worker.
- A coping skills course.
- A support group led by professionals (social worker, counsellor, psychologist).
- A support group led by patients or ex-patients.
- An informal or social gathering for patients, ex-patients, and their family members.
- A visit at diagnosis by an ex-cancer patient or long-term survivor.

The above types of services were selected since they cover the various types of services, from the most formalised (psychiatry) to the least formalised (veteran visits, informal gatherings), and they are, to varying extents, available in the Cape Town region. Most of the earlier mentioned studies which looked at utilisation and attitudes toward psychosocial care have tended to focus on one type of care, support groups being the most popular one. Including a range of services might be interesting because some comparisons in the extent of utilisation and interest can be made.

Psychological distress was assessed using the Hospital Anxiety and Depression Scale (HADS - Zigmund & Snaith, 1988) and the Beck's Depression Inventory (BDI - Beck, 1967). The HADS is a self-report scale, consisting of two sub-scales, one measuring anxiety and the other depression. Each sub-scale consists of 7 items, with each item allowing a score of 0-3 On each sub-scale a score of 0-21 is thus possible, with 8 and over indicating mild to moderate morbidity. The BDI is also a self-report scale, consisting of 21 items, with the total scale allowing scores ranging from 0-63. A score of 12 and over indicates mild depression. Depression and anxiety are the most commonly occurring forms of psychological morbidity among cancer patients (Holland, 1992), and even in

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A three point rating scale (not at all : somewhat : very much so) was used to assess the extent of interest in psychosocial interventions, the levels of social support received from family, friends, and doctor, and the attitudes toward fellow patient support. The social support literature is currently in a state of confusion, pertaining primarily to debates on the definition of social support (conceptualisation), and on how it should be measured (operationalisation) (Rose, 1990). Since our aim was furthermore to assess respondents' own *perceptions* regarding their social support needs, no attempt was made to participate in the search for the definitive construct of 'social support'. As a result, this variable was operationalised as straightforwardly as possible, utilising respondents' own terminology. In initial interviews, respondents frequently distinguished between 'support' and 'help' on the one hand, and 'understanding' on the other. Respondents were asked, in this regard, whether their family (and friends, doctor) had been helpful in dealing with their problems, and whether they had understood their problems. With regard to fellow patients, respondents were asked whether they felt fellow patients could possibly understand their problems, help them in dealing with their problems, and whether they themselves could help or support other patients. Open-ended questions dealt with possible reasons inhibiting the use of psychosocial care, main sources of support, and reasons why or why not fellow patient support may be useful.

4. PROCEDURE

Individual patients were randomly selected from the appointment book at the out-patient breast clinic at Groote Schuur Radiotherapy department, and consequently approached by the researcher in the waiting room. Potential respondents were explained that a study was being conducted in the department which involved completing a brief questionnaire, and were asked if they would care to participate. If consent was received the patient was led to a private room where the fuller purpose and procedure of the study was explained. Three potential respondents preferred not to participate in the study. Approximately half the sample of respondents completed the questionnaire in this way in the researcher's company. This allowed the respondent to query unclear or confusing issues. No significant problems were encountered in the administration of the questionnaire, and as a result the latter half of the sample completed the questionnaire on their own, either in the hospital waiting room or at home.

The results were analysed using descriptive statistical analysis. More sophisticated statistical analysis was inappropriate due to the sampling shortcomings (see below).

5. THE SAMPLE

The final sample consisted of 84 cancer patients attending the oncology out-patient clinic at Groote Schuur Hospital. Demographic characteristics of the sample are shown in Table 1. A serious shortcoming of this survey is the lack of a representative sample. Note in this regard how 87% of the sample consists of breast cancer patients. No broad generalisations can consequently be drawn from the results, particularly accross cancer type.

Table 1: Survey sample characteristics

Characteristics	No	%
*Age**		
<40	10	11.9
40-59	51	70.2
>59	23	27.4
Sex		
Male	5	6.0
Female	79	94.0
Marital status		
Married	59	70.2
Single	10	11.9
Divorced	6	7.1
Widowed	9	10.7
'Race'		
Coloured	45	53.6
Black	0	0.0
White	39	46.4
Earning status		
1	42	50.0
2	42	50.0
CaType		
Breast	73	86.9
Head & Neck	1	1.2
Lymphoma	8	9.5
Other	2	2.4
CaStage		
1	19	22.6
2	35	41.7
3	14	16.7
4	16	19.0
Treatment stage		
Radical	11	13.1
Palliative	27	32.1
Remission	46	54.8
Total	84	100

*(Mean Age=54.15 SD=11.71)

It is important to note that no Xhosa speaking people with cancer were interviewed. Very few such patients were encountered in the waiting rooms at Groote Schuur Hospital Oncology department, primarily because most Apartheid designated 'black' residential areas fall under the jurisdiction of Tygerberg Hospital. It has furthermore been noted that a large proportion of 'black' people with cancer do not seek out, or do not have access to tertiary medical care (Aucamp, 1995; Berard, 1994; Gqiba, 1994). This is a health care problem of enormous scale in South Africa, and certainly dwarfs (or makes irrelevant) the issue addressed in this thesis. If black patients are not even receiving medical treatment for their illness (for a variety of reasons - see Aucamp, 1995) then of what relevance could counselling or support services possibly be? Psychosocial perspectives could usefully be applied, however, in understanding why such populations are not being screened and treated effectively. The reader is referred to Kerner (1991, 1994) for a perspective from Harlem, New York. Such action research needs to be of an enormous scale, however, and is certainly beyond the scope of this thesis.

'Earning status' was based on the hospital payment scale, whereby the code '1' represents a monthly income of R0-1166 for single people with no dependants and R0-2166 for married people with dependants. Code '2' represents any income higher than that.

'Cancer stage' is a disease classification system indicating spread of disease. Simply put, stage 1 indicates a small localised tumour (T1 N0 M0 - breast cancer); stage 2 a larger tumour with some localised spread (e.g. T2 N2 M0 - breast cancer); stage 3 a large tumour with significant but still localised spread (e.g. T3 N3 M0 - breast cancer); and stage 4 represents any tumour with metastasis (e.g. any T any N M1 - breast cancer). Stage 1 or 2 cancers are generally treated with curative intent ('Radical'), while stage 3 and in particular stage 4 cancers are generally treated with intent to prolong life and maintain quality of life ('Palliative'). Successfully treated cancers are termed to be in 'Remission.'

6. RESULTS

6.1. DEPRESSIVE AND ANXIOUS SYMPTOMATOLOGY

Mean depression scores for the total sample were 3.48 for the HADS and 7.51 for the BDI (see Table 2). Both these means were some way below the minimum depression cut-off points of the scales. A score of 8 or more on either of the HADS sub-scales is indicative of mild to moderate psychological morbidity (depression or anxiety) (Zigmund & Snaith, 1988) and a score of 12 or more on the BDI suggests the presence of mild depression (Beck, 1967). At 6.60 the mean of the HADS anxiety scores was higher than the mean for HADS depression scores, suggesting that anxiety is a more prevalent problem than depression.

Table 2: Means and standard deviations of depression and anxiety scores.

	X	s
HADS		
Depression	3.48	3.22
Anxiety	6.60	4.51
BDI	7.51	7.58

As shown in Table 3, no more than approximately 20% of the sample scored depressed on either the BDI or HADS:Depression sub-scale. It is probable that the higher incidence of depressive symptomatology as elicited by the BDI (20.2%), compared to the HADS (10.7%), is due to the large number of neurovegetative items in the BDI. The HADS was specifically designed to avoid such items (due to overlap of chronic illness symptomatology with depression symptomatology). At approximately 35% the incidence of significant anxious symptomatology was higher, however, and affirms the higher mean of anxiety scores (compared to the depression scores).

Table 3: Incidence of significant depressive and anxious symptomatology.

	N	%
BDI	17	20.2
HADS:Depression	9	10.7
HADS: Anxiety	30	34.7
HADS: Depr or Anx	34	40.5
BDI or HADS: Depr or HADS: Anx	7	44.0

Taken together, these results indicate that approximately 44% of patients in the sample reported suffering from some form of psychological distress. It must be emphasised that these results say nothing about depressive or anxious 'disorders' as such, nor do they have anything to say about what might be causing this distress. The HADS and BDI served only as a 'thermometer', crudely measuring to what extent there might be psychosocial problems, and to what extent there might be a need (psychiatrically speaking) for various forms of psychosocial intervention. Certainly, much of the elicited distress might only be very temporary (and appropriate) reactions and thus not warrant psychosocial intervention. Perhaps more importantly for our purposes, from the patient's perspective such distress might not even be acknowledged as a pathological or aversive state to be avoided. It could, for arguments sake, be conceptualised as a time of suffering thrust upon one by a higher power to test one's faith and moral fibre. Nevertheless, from a psychiatric perspective, some support is provided for Massie, Holland, & Straker's (1990) conclusion that approximately 25% of patients and their families could be in need of some form of psychosocial intervention (without saying anything about whether these people would actually feel they need or want such intervention).

6.2. PERCEIVED SOCIAL SUPPORT, AND ATTITUDES TOWARDS FELLOW PATIENT SUPPORT

Respondents reported high levels of satisfaction with the understanding and support received from family, friends, and their doctor (see Table 4). On asked whether one's family, friends, and doctor understood one's situation and problems, and were helpful and supportive in dealing with the situation, the vast majority of respondents affirmed the 'very much so' item. With approximately 80% affirming the 'very much so' item, one's doctor was rated highest in terms of support and understanding. One's family was rated somewhat lower with only 68% of the sample affirming the 'very much so' item pertaining to perceived support. Respondents' friends were rated lowest with 60% affirming the 'very much so' item pertaining to perceived support.

On asked who their main sources of support and understanding were since being diagnosed with cancer, close to 80% of the sample identified their family and friends. Religion and the doctor were also frequently mentioned by respondents as a main source of support. In contrast, less than 5% of the sample mentioned CANSA in this regard.

Table 4: Perceived satisfaction with support from family, friends, and doctor.

	'Not at all'		'Somewhat'		'Very much so'	
	n	%	n	%	n	%
Understanding						
Family	3	3.6	17	20.2	64	76.2
Friends	6	7.1	21	25.0	57	67.9
Doctor	0	0.0	14	16.7	70	83.3
Support						
Family	4	4.8	23	27.4	57	67.9
Friends	10	11.9	24	28.6	50	59.5
Doctor	0	0.0	15	17.9	68	81.0

Although a host of factors may have influenced these results (e.g. loyalty towards family, dependency on doctor), they do point towards the conclusion that most patients *perceive themselves* to be supported by their close family, friends, and doctor. Nothing has been asserted here about 'actual' levels of social support (as an objective concept); only about *perceived* social support.

On asked whether they felt fellow patients could possibly understand the problems they were (or are) experiencing, and whether fellow patients could possibly help and support them in dealing with such problems, most respondents indicated that such understanding and support is highly feasible. Note in Table 5 how the majority of respondents affirmed the 'very much so' item regarding both the potential of being understood by fellow patients (the row marked 'understand'), and the potential of being supported by fellow patients (the row marked 'support'). It is interesting to note that over 70% of respondents felt they could support other people with cancer whereas only 60% felt they themselves could gave been (or still could be) supported by fellow patients (the row marked 'other').

Table 5: Attitudes toward fellow patient support.

	Not at all		**Somewhat**		**Very much so**	
	n	**%**	**n**	**%**	**n**	**%**
Fellow patients						
Understand	2	2.4	19	22.6	63	75.0
Support	8	9.5	25	29.8	51	60.7
Support Other	2	2.4	22	26.2	60	71.4

6.3. REPORTED UTILISATION OF VARIOUS FORMS OF PSYCHOSOCIAL CARE.

Reported use of various forms of psychosocial care was generally low. As Table 6 shows, none of the various types of psychosocial intervention, with the exception of social work and patient visits, were utilised by more than 15% of the sample.

Table 6: **Reported utilisation of various psychosocial services.**

	utilisation by respondents	
Service	**no.**	**%**
Patient Visit	40	48
SocWork	34	41
Self-help g.	11	13
Counselling	10	12
Informal g.	9	11
Prof. group	8	10
Psychiatry	7	8
Coping skills	6	7

On the other hand, 48% of the sample recalled receiving a visit from a veteran patient. Such high utilisation is due, however, to the efforts of 'Reach-for-Recovery'; a CANSA affiliated breast cancer patient organisation. This organisation attempts to visit most newly diagnosed breast cancer patients in the ward. Similarly, almost 40% of the sample reported some contact with the department social worker. Clinical experience (Berard, 1995) suggests though, that patients showing signs of emotional problems are often referred to the department social worker by the attending physician.

Although the above utilisation trends appear low, the possibility exists that different segments of the sample reported utilising different types of services. This implies therefore, that the majority of respondents may have reported utilising at least one of the reported services. The total number of respondents who reported utilising at least one service was thus calculated. A total of 58 respondents, amounting to 69% of the total sample, reported utilising at least one of the services. This is certainly a substantially higher utilisation trend, but again can be misleading due to the high reported utilisation of social work and veteran patient visits. It is important to keep in mind that in many instances contact with a social worker or veteran patient are not the result of the help seeking behaviour of the patient. Reach-for-Recovery attempts to visit most newly diagnosed breast cancer patients, and distressed patients are frequently referred to a social worker by the attending physician. If social work and patient visits are excluded from the above calculation, only 25 respondents (30% of the total sample) reported utilising any of the psychosocial services.

6.4. REPORTED INTEREST IN VARIOUS FORMS OF PSYCHOSOCIAL CARE

As shown in Table 7, over 80% of the sample expressed no interest whatsoever in seeking out the help of a psychiatrist or counsellor. Although about 15% expressed 'some' interest in seeking out these services, almost none expressed a strong interest. Interest in social work and a coping skills course was also low, although here at least 10-15% of the sample expressed 'some' interest, and another 10-15% expressed a strong interest. The lack of interest in social work supports the argument that many users of the social worker do not do so out of their own accord, but are instead referred on by medical staff. The various types of support groups enjoyed greater interest, with over 20% of the sample expressing a 'strong' interest in self-help groups and informal gatherings. Include the 'some interest' category, and it is apparent that approximately 40% of the sample expressed at least some interest in seeking out a self-help support group or informal gathering.

Table 7: Reported levels of interest in various types of psychosocial services.

	Level of interest					
Service	**'not at all'**		**'somewhat'**		**'very much so'**	
	n	**%**	**n**	**%**	**n**	**%**
Patient visit	27	32	14	17	43	51
Informal g.	47	56	19	23	18	21
Self-help g.	49	58	14	17	21	25
Prof. group	57	68	13	15	14	17
SocWork	58	70	13	15	13	15
Coping skills	65	77	10	12	9	11
Counselling	69	82	13	16	2	2
Psychiatry	70	83	13	16	1	1

Interest is thus exceptionally low in the most 'professionalised' forms of psychosocial care, with almost no patients in the sample expressing a decisive strong interest in psychiatry or counselling (1% and 2%). A minority expressed an interest in lesser professionalised services such as social work and coping skills courses (15% and 11% expressing a strong interest), and a substantial proportion of the sample expressed at least some interest in the least professionalised services such as self-help support groups or informal gatherings (25% and 21% expressing a strong interest). Interest was particularly high in veteran visits (51% expressing a strong interest), and was probably due to the fact that most patients in the sample had already experienced such a visit (and felt it was to some degree helpful).

The results regarding reported utilisation of, and reported interest in psychosocial services are illustrated in graphical terms in Figure 1. The upper three bars in each category represent the proportion of respondents who affirmed, respectively, the 'very much so', 'somewhat', and 'not at all' items regarding level of interest in the particular service. The lower bar in each category represents the proportion of respondents who reported utilising the particular service.

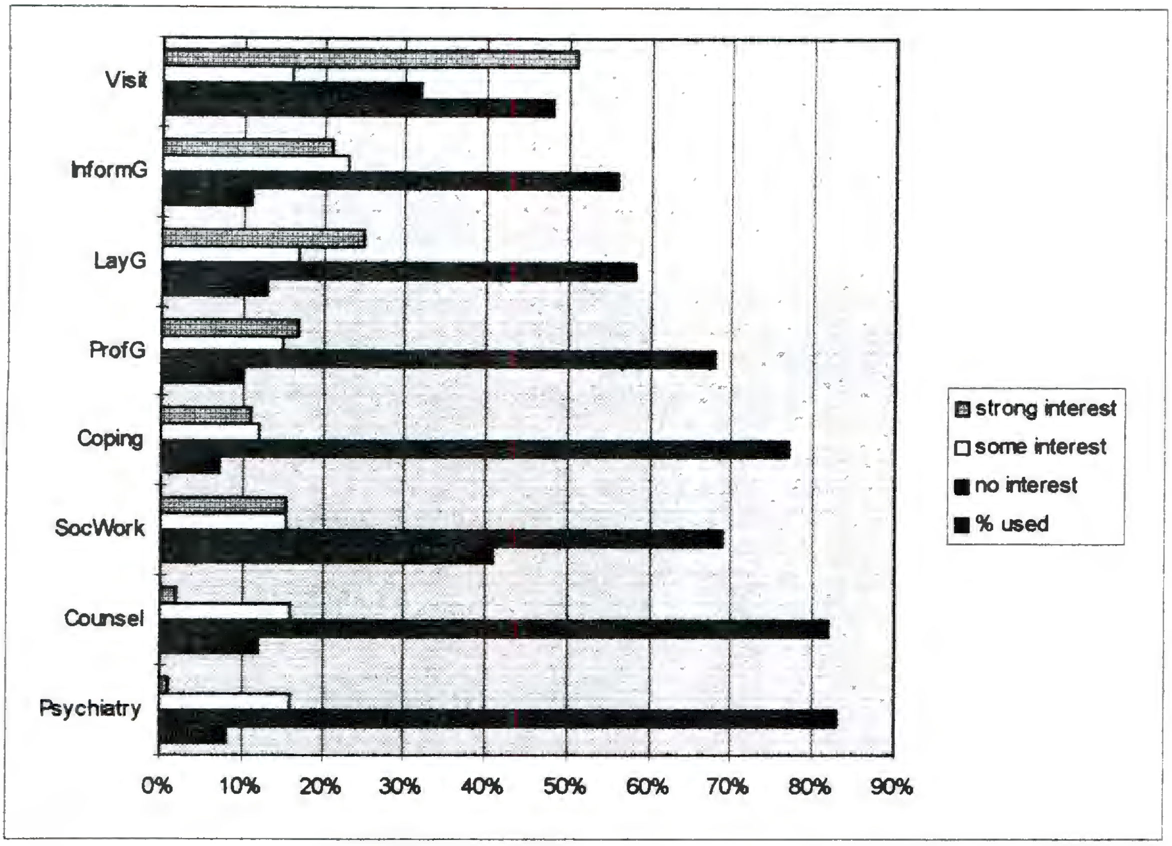

Figure 1: **% of sample reporting utilisation and interest in various forms of psychosocial care.**

As with the utilisation trends, the above results could be misleading since different segments of the sample could have expressed interest in different services. In other words, it could be that the majority of respondents expressed interest in at least one of the listed services. As such the total number of respondents who expressed interest in at least one of the services was calculated. Of the total sample, 65 respondents (77% of the total sample) expressed at least some interest in at least one of the listed psychosocial services. It could be argued that the 'somewhat' item is a rather weak expression of interest in a particular service, and as such the same analysis was conducted using only the 'very much so' item as an indicator of 'strong' interest in a particular service. In this way 61% of the total sample (51 respondents) expressed interest in at least one of the services.

Such levels of interest appear high but could be misleading due to the broad appeal of patient visits. This appeal could have been due to the broad familiarity with this service. As such, a second calculation was performed excluding interest in patient visits. In this way 61% of the total sample (51 respondents) expressed at least some interest in one of the services. Using only the 'very much so' item as an expression of interest however, only 37% of the total sample (31 respondents) expressed a strong interest in at least one of the listed services (with the exception of patient visits).

Compared to the trends observed for each individual service, these results do indicate that different people expressed interest in different services. In other words, even though the level of interest for any one service barely reached more than 40% of the total sample (with the exception of patient visits), this did not mean that 60% of the total sample expressed no interest whatsoever in any of the services. On the contrary, close to 40% of the total sample expressed no interest whatsoever in any of the services. For any one service, therefore, at least 20% of the sample who expressed no interest in that particular service, expressed an interest in at least one other service.

6.5. A COMPARISON OF RESPONDENTS WHO EXPRESSED AN INTEREST IN PSYCHOSOCIAL SERVICES AND RESPONDENTS WHO EXPRESSED NO INTEREST IN PSYCHOSOCIAL SERVICES.

The results shown above suggest that utilisation of a particular psychosocial service does not necessarily imply that this person wanted to utilise that service. With regard to social work, for example, a substantial proportion of the sample reported having had contact with such a professional, but a substantially smaller proportion of the sample expressed any interest in ever consulting a social worker. Berard (1995) has suggested, in this regard, that distressed people with cancer are referred to the social worker by an authoritative figure (e.g. the doctor). Although a medically orientated system of care based on such referral paths could very well 'work' in first world countries, this author is of the opinion that such authoritarian systems of care are both archaic and inappropriate for dealing with psychosocial issues in South Africa (where primary care is limited).

Psychosocial issues are not necessarily medical issues, and even if they were, a traditional medical system is not necessarily capable of servicing all sectors of the population equally. Kerner (1992, 1994) has repeatedly argued and empirically shown, how traditional health care approaches alienate socio-economically disadvantaged populations. As such, this thesis is concerned with the notion of a *consumer-friendly* system of psychosocial care; a system of care which is capable of attracting as broadly as possible, the people who might require and benefit from its services. As a result the subsequent analyses of the results will focus primarily on expressed interest in psychosocial services, as opposed to reported utilisation of psychosocial services. It is acknowledged that expressed interest does not necessarily translate into utilisation, but it is considered an essential ingredient to a consumer-friendly system of care.

In subsequent sections analysed results pertaining to each type of psychosocial care are presented. For each type of psychosocial service the sample was split into those respondents affirming the 'not at all interested' item and those affirming either the 'somewhat interested' or 'very much so interested' items. In other words, the sample was split into respondents expressing no interest in the service whatsoever, and respondents showing at least *some* interest, whether moderate or strong. The characteristics of each sub-sample were then compared using two-sample t-tests for ordinal data (age, HADS and BDI scores, satisfaction with support from family, friends, and doctor, and attitudes toward fellow patient support) and chi-square tests for categorical data ('race', marital status, earning status, cancer stage, and treatment stage) (Howell, 1992). The means pertaining to fellow patient support were calculated by averaging respondents' ratings on a 3-point scale (1=not at all, 2=somewhat, 3=very much), expressing their attitude toward fellow patients being capable of '*understanding*' them, '*supporting*' them, and whether they would be capable of supporting '*other*' patients. The social support means were calculated in the same manner except that the scores on the 'understanding' and 'support' items were added together, giving scores out of 6.

Full versions of the tables are presented in section 6.5.1. For the sake of clarity and brevity, however, in ensuing sections only statistically significant data are presented. Complete versions of the tables can be found in Appendix B.

6.5.1. PSYCHIATRY

As shown in Table 8, on the variables 'race', marital status, earning status, cancer stage and treatment stage, no statistically significant differences were found between respondents who expressed an interest in psychiatry and those who expressed no such interest.

Table 8: Chi-square values for respondents expressing no interest versus some interest in psychiatry, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest O(E)	Some interest O(E)	chi sq. value	df	significant
	N	70	14			
	% of total sample	83.30%	16.70%			
Demographics						
'Race'						
	White	32 (32.9)	7 (6.5)	0.125	1	NS*
	Coloured	39 (38.9)	7 (7.7)			
Marital Status						
	Married	49 (49.2)	10 (9.8)	0.011	1	NS*
	Single/D/W	21 (20.8)	4 (4.2)			
Earning status						
	1	37 (35)	5 (7)	1.371	1	NS*
	2	33 (35)	9 (7)			
Cancer stage						
	1	14 (15.8)	5 (3.2)	3.204	3	NS**
	2	32 (29.2)	3 (5.8)			
	3	11 (11.7)	3 (2.3)			
	4	13 (13.3)	3 (2.7)			
Treatment stage						
	Radical	8 (9.2)	3 (1.8)	2.604	2	NS***
	Palliative	21 (22.5)	6 (4.5)			
	Remission	41 (38.3)	5 (7.7)			

* **critical value at $p<0.05= 3.84$**
** **critical value at $p<0.05= 7.82$**
*** **critical value at $p<0.05= 5.99$**

As shown in Table 9, respondents expressing some interest in psychiatry scored significantly higher on the HADS sub-scales, and were significantly less satisfied with the support and understanding received from their doctor. No other statistically significant differences were found, although it was apparent that respondents expressing some interest in psychiatry were generally younger (age; x= 47,86) than those expressing no such interest (age; x= 55.41).

Table 9: Means and two-sample t-test p values for respondents expressing no interest versus some interest in psychiatry, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	70	14			
	% of total sample	83.30%	16.70%			
Demographics						
	Age	55.41	47.86	1.882	16	0.078 NS
Psychological distress						
	HADS:Depr	3.11	5.21	2.122	17	0.049 S
	HADS:Anx	5.96	9.29	2.682	19	0.015 S
	BDI	6.40	12.36	2.051	15	0.058 NS
Support						
	Family	5.39	5.21	0.559	18	0.583 NS
	Friends	5.09	5.00	0.264	18	0.794 NS
	Doctor	5.74	5.07	2.114	15	0.049 S
Attitudes toward fellow patient support						
	Understand	2.70	2.86	1.363	25	0.185 NS
	Support	2.51	2.50	0.066	17	0.948 NS
	Other	2.67	2.79	0.877	22	0.389 NS

6.5.2. PSYCHOTHERAPY AND COUNSELLING

As shown in Table 10, a lower proportion of low earning status respondents and a higher proportion of high earning status respondents than expected expressed an interest in psychotherapy and counselling.

Table 10: Chi-square values for respondents expressing no interest versus some interest in psychotherapy and counselling, on "race", marital status, earning status, and time since diagnosis.

Variables	No interest O(E)	Some interest O(E)	chi sq. value	df	significant
N	69	15			
% of total sample	82.14%	17.86%			
Earning status					
1	39 (34.5)	3 (7.5)	6.57	1	S*
2	30 (34.5)	12 (7.5)			

* critical value at $p<0.05$= 3.84

Note in Table 11 that respondents expressing some interest in psychotherapy and counselling were significantly younger and scored significantly higher on the anxiety sub-scale of the HADS. With regard to fellow patient support, respondents expressing some interest in psychotherapy and counselling were more inclined to believe that fellow patients could understand their problems and situation than respondents expressing no interest in psychotherapy and counselling. Although no other statistically significant differences were found, it was evident that respondents expressing some interest in psychotherapy and counselling were generally less satisfied with the support and understanding received from their doctor compared to respondents expressing no such interest. A few more 'white' respondents than expected expressed an interest in psychotherapy and counselling, and conversely, a few less 'coloured' respondents than expected expressed no interest in psychotherapy and counselling.

Table 11: Means and two-sample t-test p values for respondents expressing no interest versus some interest in psychotherapy and counselling, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	69	15			
% of total sample	82.14%	17.86%			
Demographics					
Age	55.39	48.47	2.190	21	0.039 S
Psychological distress					
HADS:Anx	5.86	9.53	3.137	21	0.005 S
Attitudes toward fellow patient support					
Understand	2.68	2.93	2.737	44	0.009 S

6.5.3. SOCIAL WORK

As shown in Table 12, respondents expressing some interest in consulting a social worker were significantly younger, and scored significantly higher on the BDI. With regard to fellow patient support, respondents expressing some interest in social work were more inclined to believe that fellow patients could understand their problems and situation than respondents expressing no interest in social work. No other statistically significant differences were found. It was nevertheless of interest to note, however, that the proportion of low earning status respondents expressing an interest in social work was somewhat higher than expected (see Table 13). It was furthermore apparent that the proportion of 'coloured' respondents expressing an interest in social work was somewhat higher than expected (see Table 13).

Table 12: Means and two-sample t-test p values for respondents expressing no interest versus some interest in social work, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	58	26			
	% of total sample	69.05%	30.95%			
Demographics						
	Age	55.95	50.15	2.481	69	0.015 S
Psychological distress						
	BDI	6.16	10.15	2.052	37	0.047 S
Attitudes toward fellow patient support						
	Understand	2.66	2.88	2.385	75	0.020 S

Table 13: Chi-square values for respondents expressing no interest versus some interest in social work, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	significant
	N	58	26			
	% of total sample	69.05%	30.95%			
"race"						
	white	31(26.9)	8(12.1)	3.710	1	NS*
	coloured	27(31.1)	18(13.9)			
Earning status						
	1	26 (29)	16 (13)	2.005	1	NS*
	2	32 (29)	10 (13)			

*** critical value at $p<0.05 = 3.84$**

6.5.4. COPING SKILLS COURSE

As shown in Table 14, respondents expressing some interest in attending a coping skills course were significantly younger, scored significantly higher on the HADS:Anxiety sub-scale, and were less satisfied with the support and understanding received from their family. No other statistically significant differences were found. In Table 15, however, note how a somewhat higher proportion than expected of respondents receiving radical treatment expressed an interest in a coping skills course. Conversely, a lower proportion than expected of respondents on palliative treatment expressed an interest in a coping skills course.

Table 14: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a coping skills course, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	65	19			
	% of total sample	77.38%	22.62%			
Demographics						
	Age	55.98	47.89	2.957	33	0.006 S
Psychological distress						
	HADS:Anx	5.80	8.95	3.086	34	0.004 S
Support						
	Family	5.52	4.79	2.178	22	0.040 S

Table 15: Chi-square values for respondents expressing no interest versus some interest in a coping skills course, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	significant
	N	65	19			
	% of total sample	77.38%	22.62%			
Treatment stage						
	Radical	6 (8.5)	5 (2.5)	4.237	2	NS***
	Palliative	23 (20.9)	4 (6.1)			
	Remission	36 (35.6)	10 (10.4)			

***** critical value at $p<0.05= 5.99$**

6.5.5. PROFESSIONAL SUPPORT GROUP

As shown in Table 16, respondents expressing some interest in attending a professional support group were significantly younger, scored significantly higher on the HADS: anxiety sub-scale, and were less satisfied with the support and understanding received from their family. No other statistically significant differences were found.

Table 16: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a professional support group, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	59	25			
	% of total sample	70.24%	29.76%			
Demographics						
	Age	56.58	49.04	3.164	65	0.002 S
Psychological distress						
	HADS:Depr	2.95	4.56	1.997	40	0.053 NS
	HADS:Anx	5.72	8.19	2.371	49	0.022 S
Support						
	Family	5.58	4.89	2.571	36	0.014 S

6.5.6. SELF-HELP SUPPORT GROUP

As shown in Table 17, respondents expressing some interest in attending a self-help support group were significantly younger, scored significantly higher on both HADS sub-scales, and were less satisfied with the support and understanding received from their doctor. No other statistically significant differences were found.

Table 17: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a self-help support group, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	49	35			
	% of total sample	58.33%	41.67%			
Demographics						
	Age	56.43	50.97	2.171	76	0.033 S
Psychological distress						
	HADS:Depr	2.80	4.40	2.258	63	0.027 S
	HADS:Anx	5.53	7.89	2.424	72	0.018 S
Support						
	Family	5.59	5.03	2.409	56	0.019 S

6.5.7. INFORMAL GATHERINGS

As shown in Table 18, respondents expressing some interest in attending an informal gathering were less satisfied with the support and understanding received from their family. Although no other statistically significant differences were found, it was evident that respondents expressing some interest in attending an informal gathering were, on average, somewhat younger, and were more inclined to believe that fellow patients could understand their problems and situation than respondents expressing no interest.

Table 18: Means and two-sample t-test p values for respondents expressing no interest versus some interest in an informal gathering, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	47	37			
%	55.95%	44.05%			
Demographics					
Age	56.19	51.57	1.835	79	0.070 NS
Support					
Family	5.57	5.08	2.127	57	0.038 S
Attitudes toward fellow patient support					
Understand	2.64	2.84	1.934	80	0.057 NS

6.5.8. VETERAN PATIENT VISITS

Note in Table 19 that a lower proportion than expected of low earning status respondents, and a higher proportion than expected of high earning status respondents expressed an interest in veteran visits. Note furthermore that a lower proportion than expected of respondents with stage 4 cancer, and a higher proportion than expected of respondents with stage 1 and 2 cancer expressed an interest in veteran visits. Probably related to this, also note that a lower proportion of respondents than expected on palliative treatment expressed an interest in veteran visits.

Table 19: Chi-square p values for respondents expressing no interest versus some interest in a patient visit, on "race", marital status, earning status, and time since diagnosis.

Variables	No interest	Some interest	chi sq. value	df	Significant
N	28	56			
%	33.3%	66.7%			
Earning status					
1	20 (14)	22 (28)	7.714	1	S*
2	8 (14)	34 (28)			
Cancer stage					
1	4 (6.3)	15 (12.7)	12.085	3	S**
2	8 (11.7)	27 (23.3)			
3	5 (4.7)	9 (9.5)			
4	11 (5.3)	5 (10.7)			
Treatment stage					
Radical	4 (3.7)	7 (7.3)	9.969	2	S***
Palliative	15 (9)	12 (18)			
Remission	9 (15.3)	37 (30.7)			

* **critical value at $p<0.05= 3.84$**
** **critical value at $p<0.05= 7.82$**
*** **critical value at $p<0.05= 5.99$**

As shown in Table 20, respondents expressing some interest in a veteran patient visit scored significantly higher on the HADS: anxiety sub-scale, and were more inclined to believe that fellow patients could understand their problems and situation, and could potentially have helped and supported them in dealing with their problems, than respondents expressing no interest. No other statistically significant differences were found.

Table 20: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a patient visit, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	28	56			
%	33.3%	66.7%			
Psychological distress					
HADS:Depr	2.63	3.93	1.955	67	0.055 NS
HADS:Anx	4.30	7.61	3.554	62	0.001 S
Attitudes toward fellow patient support					
Understand	2.52	2.84	2.572	39	0.014 S
Support	2.30	2.63	2.028	45	0.049 S

6.6. UTILISATION AND INTEREST IN VARIOUS TYPES OF PSYCHOSOCIAL CARE AMONG PSYCHOLOGICALLY DISTRESSED SCORING RESPONDENTS.

It was suggested earlier that the apparent lack of interest in psychosocial services is due to the possibility that most respondents experience no psychosocial problems and thus have no need to seek out help. Approximately 44% of this sample showed some evidence of being psychologically distressed, however, thus refuting that suggestion. The prevalence of psychological distress is, after all, the primary reason why psychosocial services are designed and implemented at all. As such, a system of psychosocial care should be attracting psychologically distressed people with cancer (its 'target market'). The results presented in section 6.2. show that this is, to an extent, the case. For nearly all types of psychosocial care, those respondents who expressed at least some interest in the service, scored on average higher on the psychological morbidity rating scales than those respondents expressing no interest.

As shown in Figure 2, the reported utilisation and interest in psychiatry in the distressed scoring group was only marginally higher than that of the total sample. Less than 20% of the distressed scoring respondents reported having any contact with a psychiatrist, and none of these respondents expressed a strong interest in seeking out such contact. A slightly higher proportion of distressed scoring respondents expressed 'somewhat' interest in consulting a psychiatrist.

6.6.2. PSYCHOTHERAPY AND COUNSELLING

The results pertaining to psychotherapy and counselling are almost identical to those regarding psychiatry. The reported utilisation was only marginally higher at 15-20% of the distressed scoring sample, and no more than 2% expressed a strong interest in seeking out such services. Again, a slightly higher proportion of distressed scoring respondents expressed 'somewhat' interest in consulting a psychotherapist or counsellor.

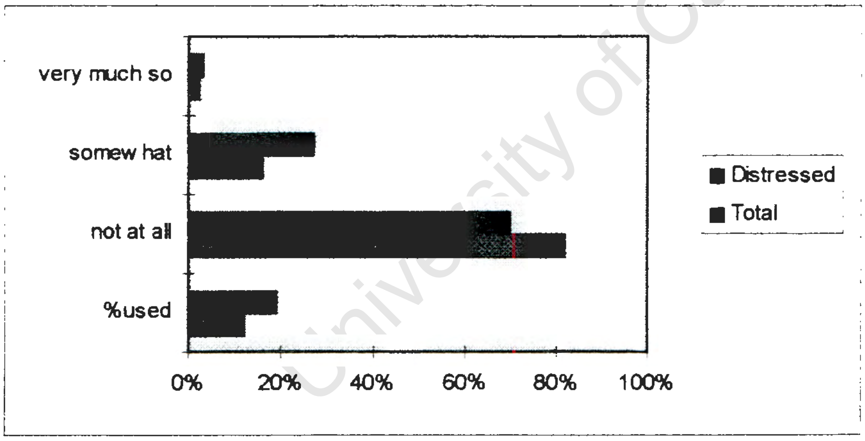

Figure 3: Use of, and interest in counselling or psychotherapy among depressed and anxious scoring patients.

6.6.3. SOCIAL WORK

Close to 50% of the depressed and anxious scoring sample reported having had contact with the department social worker, which is approximately 10% higher than the total sample utilisation proportion (see figure 4). As discussed earlier, this high utilisation is probably due to the possibility that most distressed patients are referred on to the social worker by an authoritative figure (e.g. doctor). The concurrent lack of interest in social work (less than 20% expressing a strong interest) lends support to the notion that most of this utilisation is not due to the help-seeking efforts of respondents, but is due to the system of referral.

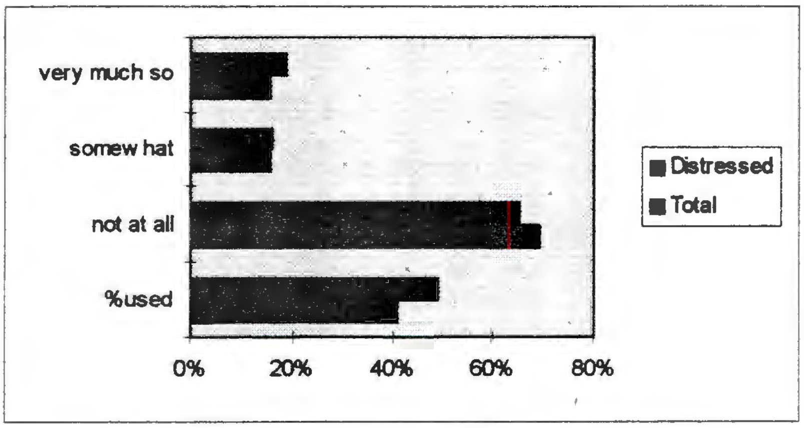

Figure 4: Use of, and interest in social work among depressed and anxious scoring patients.

6.6.4. COPING SKILLS COURSE

Up to 36% of distressed scoring respondents expressed at least some interest in attending a coping skills course, with close to 15% expressing a strong interest (see Figure 5). This is a somewhat higher percentage than the marginal proportion of respondents who actually attended a course, suggesting that a number of distressed individuals would like to attend a course but for some reason do not do so. As with psychiatry and psychotherapy/counselling, note again how a slightly higher proportion of distressed scoring respondents expressed 'somewhat' interest in consulting a psychotherapist or counsellor. Nevertheless, interest in this service was no higher than the interest expressed in social work.

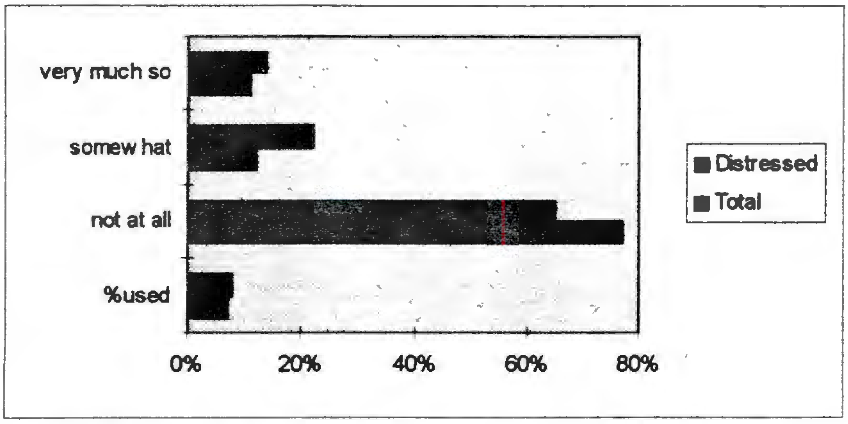

Figure 5: Use of, and interest in a coping skills course among depressed and anxious scoring patients.

6.6.5. PROFESSIONAL SUPPORT GROUP

Utilisation trends and levels of interest in this service were only slightly higher among psychologically distressed respondents than those observed in the total sample (see Figure 6). Just over 40% of the distressed scoring sub-sample expressed at least some interest in attending a professional support group. Again, however, these results are hardly different to those pertaining to a coping skills course and social work. It is interesting to note once again the slightly higher proportion of distressed scoring respondents who expressed 'somewhat' interest in consulting a psychotherapist or counsellor

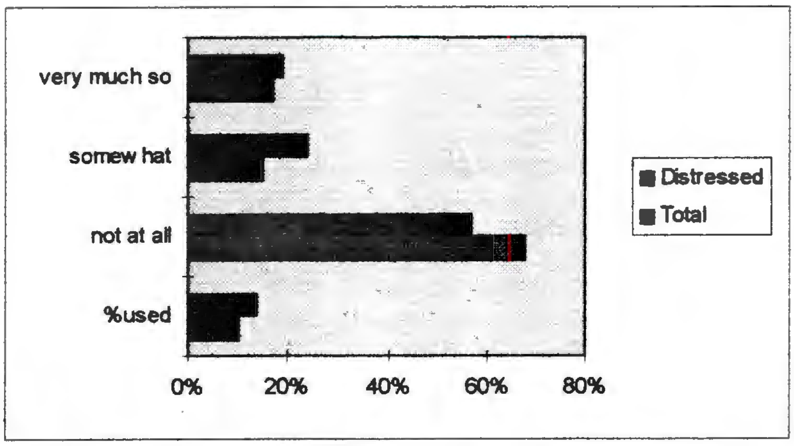

Figure 6: Use of, and interest in a professionally run support group among depressed and anxious scoring patients.

6.6.6. SELF-HELP SUPPORT GROUP

A relatively high proportion of distressed scoring respondents (close to 35%, compared to 25% in the total sample) expressed a 'strong' interest in self-help groups (see Figure 7). Over 50% of the distressed scoring sample expressed at least some interest in attending a self-help group. Only in this category was there any apparent substantial difference in the level of interest for the service between the total sample and the distressed sample.

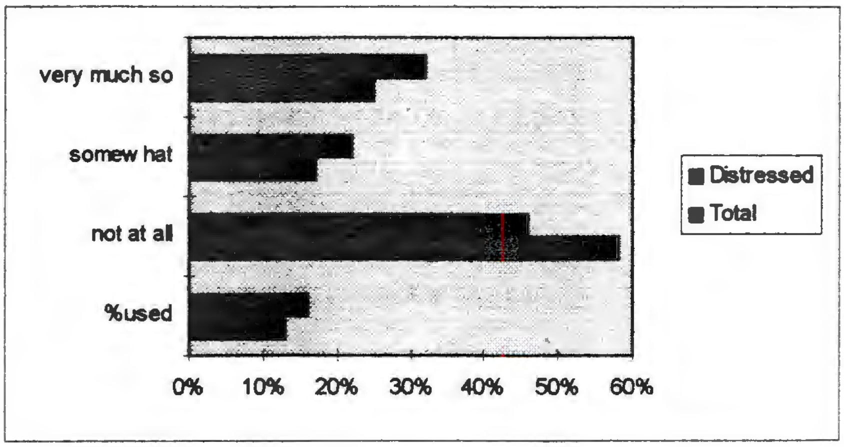

Figure 7: Use of, and interest in a self-help group among depressed and anxious scoring patients.

6.6.7. INFORMAL GATHERING

As shown in Figure 8, approximately 45% of the distressed scoring sample expressed at least some interest in attending an informal gathering. This is a substantial amount of interest but appears to be hardly different to the trends observed in the total sample.

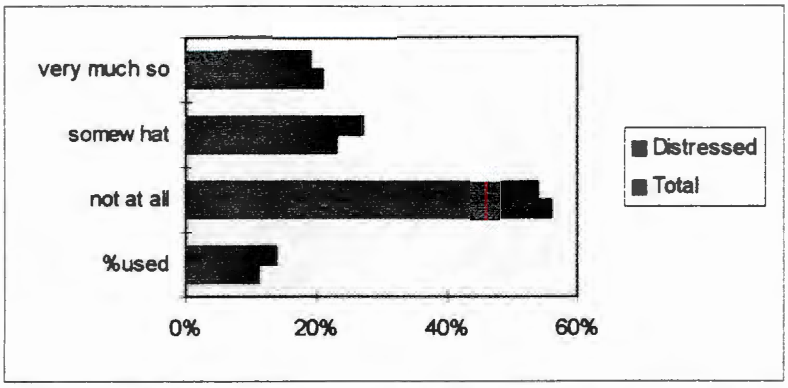

Figure 8: Use of, and interest in an informal gathering among depressed and anxious scoring patients.

6.6.8. VETERAN PATIENT VISIT

The veteran patient visit managed to attract the most interest in this sample of psychologically distressed scoring respondents. As shown in Figure 9, over 70% of the distressed scoring respondents expressed an interest in the concept of a veteran patient visit (worked out by adding the 'somewhat' and 'very much so' categories). Particularly striking is the high level of *strong* interest in this service. Note that over 60% of the distressed scoring sample affirmed the 'very much so' response.

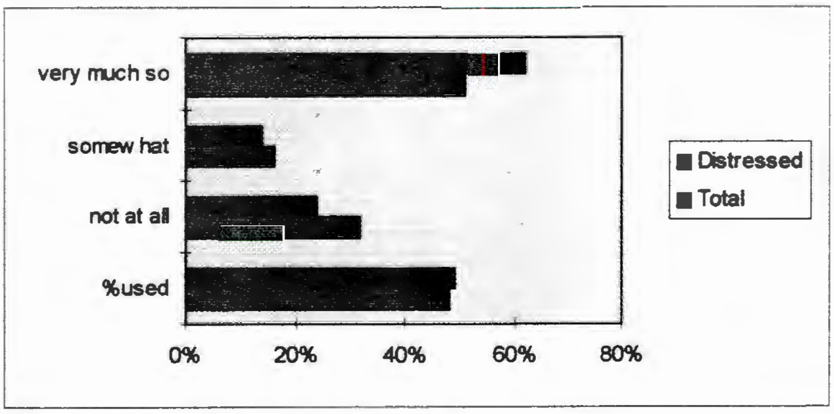

Figure 9: Use of, and interest in a patient visit among depressed and anxious scoring patients.

To sum up, Figure 10 compares the level of interest in various psychosocial services among psychologically distressed respondents. The upper bars represent the proportion of respondents who affirmed the 'very much so' item, and the lower bars represent the proportion of respondents who affirmed the 'somewhat' item. Note how interest in the more 'professionalised' forms of psychosocial care such as psychiatry, and psychotherapy/counselling, remain exceptionally low among distressed scoring respondents, with almost no respondents in this sub-sample expressing a decisive strong interest in psychiatry or counselling.

Interest in social work and a coping skills course was higher, with at least a small proportion of respondents expressing a strong interest in these services. Interest in a professionally run support group and an informal group was even greater, but only slightly higher to the level observed in the total sample.

Note in Figure 10, however, how the 'very much so' bars peak at self-help groups and patient visits, clearly identifying these two services as the most appealing services to the psychologically distressed scoring respondents. Furthermore, a notable difference in the level of interest in these services between the psychologically distressed scoring sub-sample and total sample was also observed (see Figures 7 and 9). Whereas approximately 25% of the total sample expressed a 'strong' interest in attending a self-help group, 32% of the distressed scoring sample expressed such a 'strong' interest. Similarly, close to 65% of the distressed scoring sample expressed a strong interest in the concept of veteran patient visits (as opposed to approximately 50% of the total sample). It appears therefore, that self-help support groups and veteran patient visits were particularly successful in appealing *powerfully* and *specifically* to psychologically distressed respondents.

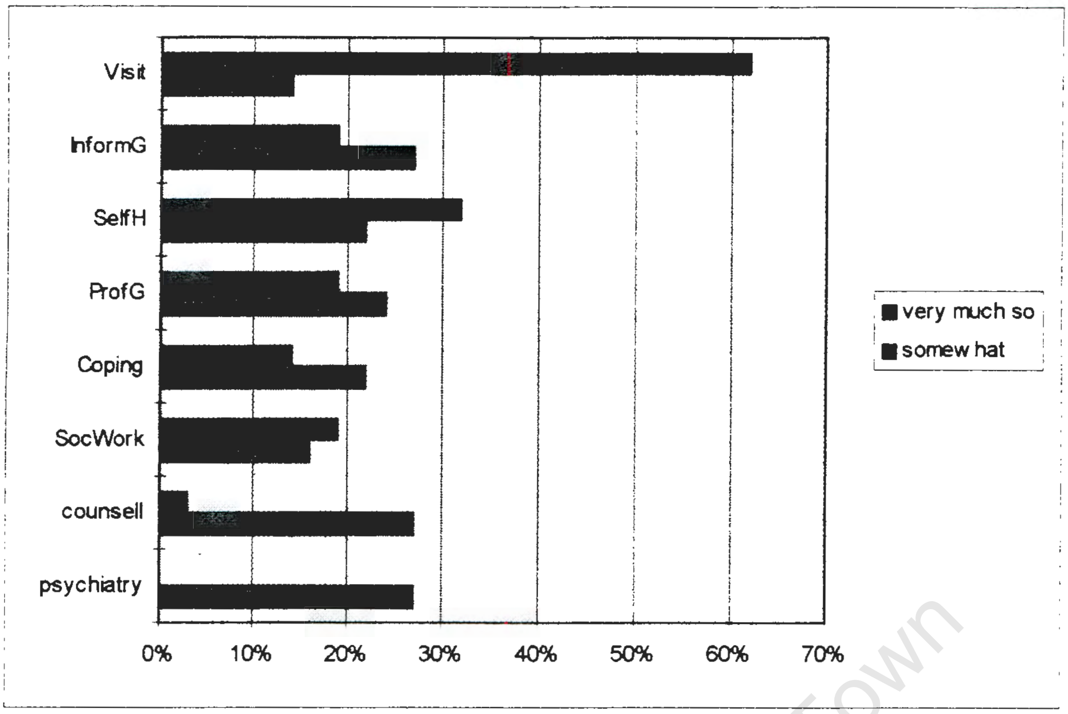

Figure 10: Level of interest in various psychosocial services among psychologically distressed scoring respondents.

6.7. COMPARING RESPONDENTS INTERESTED IN DIFFERENT TYPES OF PSYCHOSOCIAL CARE.

The previous analysis highlighted the broad appeal of self-help groups and veteran patient visits among psychologically distressed respondents. A question to be posed therefore, is whether self-help groups and veteran patient visits are *generally* more appealing, or whether they appeal to specific types of people - people perhaps over-represented in our sample. De Bocanegra (1992), for example, has noted that people of lower socio-economic status are more likely to be interested in support groups compared to people of higher socio-economic class. It could be, for example, that the low utilisation and interest trends observed in the present sample, are simply due to different types of people expressing interest in different types of services. This possibility was at least partly addressed in sections 6.3. and 6.4, by calculating the total number of respondents who utilised at least one of the listed services, and the total number of respondents who expressed interest in at least one of the services. In this manner some indication was provided that different people might be interested in different types of services, since the total level of interest in *a* psychosocial service, regardless of type, was higher than the level of interest observed in any one service.

By comparing the demographic characteristics of respondents who expressed an interest in each service versus those who expressed no interest, further indication was provided that different types of services could appeal to different types of people. For example, more high-earning status respondents and fewer low earning status respondents than expected expressed an interest in psychotherapy and counselling. Conversely, social work appeared to appeal to more low earning status respondents than expected. De Bocanegra's (1992) hypothesis was not supported, however, since respondents expressing an interest in various support groups were no different on the variable 'earning status' than respondents expressing no such interest. In fact, veteran patient visits appealed to more high earning status respondents than expected. In context of the present sample size, these results are decidedly flimsy and thus serve no other purpose besides suggesting the hypothesis that different people (particularly along socio-economic status lines) could be interested in different types of services.

It is however difficult to make sense of the level of interest in psychosocial services when no indication is given as to what proportion of respondents would actually need psychosocial services. As argued earlier, psychologically distressed people are, in theoretical terms, people who need psychosocial care. As such the earlier analysis in section 6.4. was repeated using the sub-sample of respondents scoring distressed on either the BDI, HADS:Depression sub-scale, or HADS:Anxiety sub-scale. This sub-sample consisted of 37 respondents (44% of the total sample).

In this regard 86.5% of the distressed scoring sample (32 out of 37 respondents) expressed an interest in at least one of the listed services. By only using the 'very much so' item as an expression of interest, however, 70.3% of the distressed scoring sample (26 respondents) expressed an interest in at least one service. Such high levels of interest are to be expected considering that patient visits - the most appealing service for this sample - appealed to close to 80% of this sample.

As argued earlier, the high level of interest in patient visits could have been due to the broad familiarity with this service, thus biasing this service in our comparisons. If patient visits are excluded from the analysis close to 30% of the distressed scoring sample (11 respondents) expressed no interest whatsoever in any of the psychosocial services except veteran patient visits. Significantly, close to 60% of this sample (22 respondents) did not express a *strong* interest in any of the listed services except patient visits. With regard to the level of *strong* interest therefore, the proportion is no different to that observed in the total sample. Only 40% of distressed scoring respondents expressed a strong interest in at least one of the services (with the exception of patient visits).

These results do indicate once again, that to some extent, different people are interested in different services. For example, 32% (n=12) of the distressed scoring sample expressed a strong interest in self-help groups, implying that another 8% of the distressed scoring sample expressed a strong interest in at least one other service except patient visits (since 40% of the distressed scoring sample expressed an interest in at least one of the listed services - except patient visits). If patient visits are included the above 8% would become 38% (since 70% of the distressed scoring sample expressed an interest in at least one of the listed services).

Although the present results indicate that to some extent different people expressed an interest in different services, it was difficult if not impossible to identify different segments of the sample which may be interested in different services. The psychologically distressed sub-sample was too small and homogeneous for such an analysis.

6.8. THE QUALITATIVE DIMENSIONS OF THE QUESTIONNAIRE: A CONTENT ANALYSIS.

6.8.1. REASONS FOR NOT UTILISING PSYCHOSOCIAL SERVICES.

Respondents were asked to mention some of the barriers preventing them from using a particular service if they did at any stage want to use that service. A large variety of responses were elicited in this way making a meaningful content analysis impossible. For one, the majority of respondents left this question unanswered, even if they indicated elsewhere that they were interested in at least one type of psychosocial service. A brief list of the type of responses to this item, including the approximate percentage of respondents (N=131) who expressed such a reason, follows:

- Practical reasons (time, transport, cost, lack of information) (5%)

- CANSA does not show any interest, CANSA does not care (3%)
  "not enough personal contact"
- Respondent feels he or she is coping fine (4%)
  "I know what it all entails"
  "I have a positive attitude and feeling about things.."
  "I did not feel that I needed any of the services available. The melanoma has not changed me, nor my outlook on life in general."
- Respondent claims to have faith in God and therefore requires no services (5%)
  "..and above all I am a Christian and I trust God for his will and his purpose in life."
  "my belief in God's promise carries me through"
- Respondent claims to have faith in the doctor and therefore requires no services (3%)
  "I have a positive attitude and feeling about things, because I co-operate with the doctor and treatment."

"I have complete faith and trust in my doctor and surgeon, as well as my treatment.."

- Withdrawal and social isolation (1%)

  "couldn't talk, was alone, by myself"

- Respondent acknowledges that he or she was in a state of denial. (1%)

  "don't want to talk about it, block it out"

- Respondent thought that he or she had the strength to cope by herself (2%)
- Lack of confidence to look for help (1%)
- Coping is a matter of acceptance (2%)

  "the sooner you accept it the better"

- Stigma of psychosocial services (3%)

  "for mad people"

  "for lonely people, who don't have much to do"

  "for people who are doing poorly medically"

- Claims to have sufficient support (2%)

6.8.2. REASONS WHY PSYCHOSOCIAL SERVICES COULD HELP

On asked why psychosocial services could be of benefit, the majority of respondents expressed reasons pertaining in some way to fellow patient support.

- The sharing of similar experiences. Sharing one's fears with fellow patients. (16%)

  "talking with fellow patient makes me feel much richer"

  "to hear other people express your fears and emotions allows the patient to understand that these are normal feelings"

A host of other reasons were also expressed, some of which follow below:

- Provides encouragement (2%)

- "life must go on, not the end of the line yet"

- Speaking to someone helps (1%)
- Encourage the patient to comply with treatment (1%)

It is interesting to note that most people who expressed an interest in psychosocial care, justified their sentiments by referring to the supposed beneficial effects in fellow patient support. This pattern was indirectly reflected by the positive attitudes expressed toward fellow patient support in the rating scale, an ironic finding when contrasted with the lack of interest in any psychosocial services.

6.8.3. REASONS WHY FELLOW PATIENTS CAN, OR CANNOT SUPPORT EACH OTHER.

On asked why fellow patients can help and support each other, a substantial number of respondents focused on three themes:

- The sharing of experience and fears (12%)
- Fellow patients have had similar experiences. They understand each other's pains, fears and anxieties. (13%)
- Encouragement, morale boost, positive attitudes, motivation, model patients (12%)
  "positive thinking, positive conversation"

A variety of other explanations were provided, some of which pertain almost directly to the above two themes:

- Enjoyment in talking, chatting (5%)
- It eases emotional distress and uncertainties. Normalises fears and emotions. (5%)
  "to hear other people express your fears and emotions allows the patient to understand that these are normal feelings"
- Practical help and advice (3%)

Some respondents expressed reasons why they felt fellow patients would not be able to give support. Most of such explanations centred around the suspicion that fellow patients would depress each other.

- Fellow patients can depress one another (8%)

  "..wallow in depression.."
  "too wrapped up in own problems"
  "depresses you , like watching movie with dying people"

A minority of respondents felt that fellow patient support could be useful, only if certain conditions were met:

- Patients need the required skills (e.g. need to be willing to listen) (2%)
- Some group homogeneity is required (disease severity, 'culture') (2%)

7. SHORTCOMINGS OF THE SURVEY

Since the survey sample was substantially skewed toward 'white' and 'coloured' female breast cancer patients, the present results are not generalizable to other cancer types, nor to males with cancer, 'black' people with cancer, and nor to people with cancer in other geographical areas. A truly representative sample is difficult to conceptualise however, since the population in question is itself difficult to define. Who do we define as a 'person with cancer' for example? Can we really say that a person diagnosed and successfully treated 30 years ago is a 'cancer patient?' Nevertheless, such are the types of people one encounters at the oncology out-patient clinic, and such people may even be clinically depressed. The study question is, in one sense, a very practical issue, and the research itself has also had to cope with a range of practical limitations and constraints (see Van Dam & Aaronson, 1987). For example, interviewing a more ethnically representative sample of cancer patients may be possible, but in logistical terms this was completely out of range for this thesis. Such constraints need to be acknowledged so that we can be clear about who it is we have interviewed, and in what way such factors may have played a role in determining the nature of our results. This study is very definitely an example of applied research and as such the presence of 'contaminating variables' are not only unavoidable but actually define the very nature of the research.

The questionnaire was not an objective measuring instrument of attitudes towards psychosocial care, social support, and fellow patient support. 'Objectivity' in social research depends on valid conceptualisations and operationalisations of particular concepts (e.g. what is the meaning of 'social support' and how do we measure it), a task which usually involves a great deal of pre-testing and subsequent questionnaire refinement. Due to logistical reasons, this task was only approximated by utilising earlier interviews and designing as straightforward and simple a questionnaire as possible, asking people about their perceptions regarding the various issues. The present survey, therefore, did not measure the amount of social support received by respondents from various sources. On the contrary, it elicited trends regarding respondents' perceived satisfaction with the support and understanding received from various sources. Similarly, the level of interest expressed in a particular psychosocial service is by no means an indication of whether that respondent will actually seek out such a service. All it represents is respondents' expressed interest; something which can be assumed to be a reasonably vital ingredient toward the goal of a consumer-friendly system of care.

In the questionnaire, a distinction should possibly have been made between counselling and psychotherapy, since the results presented in chapter 5 do suggest that people perceive differences between the two services. The two services were combined in one item since it was presumed that people would have difficulty telling the difference between the two services.

8. DISCUSSION

As discussed above, the present sample does represent a sizeable proportion of cancer patients attending the Groote Schuur Hospital out-patient oncology clinic. The majority of the respondents, in this regard, were middle aged, married woman of middle to lower socio-economic status, with relatively early stage disease in complete or partial remission. The prevalence of depressive symptomatology was relatively low, but similar to levels reported elsewhere (Massie & Holland, 1990). The prevalence of anxious symptomatology was high, however, and contradicts some of the trends found elsewhere in the world (Chaturverdi, Chandra, Channabasavanna, Beena, & Pandian, 1994; Hopwood, Howell & Maguire, 1991). It was unclear as to why anxiety was so prevalent in our sample, although one could speculate that the general situational context might have something to do with it. South African society is in a state of transition, with socio-economically disadvantaged people in particular facing a range of serious social problems (e.g. crime, unemployment). One can only presume that a cancer diagnosis would not make life easier.

Notwithstanding the levels of anxiety, the majority of respondents did report a high degree of satisfaction with the support received from family, friends and doctor. Interestingly, most respondent were also positively inclined toward the concept of fellow patient support.

The results pertaining to the utilisation of psychosocial care were reasonably consistent with those reported elsewhere (e.g. Bauman, Gervey, & Siegel, 1992; De Bocanegra, 1992; Taylor, Falke, Shoptaw, & Lichtman, 1986; Tishelman & Sachs, 1994; Worden & Weisman, 1984), and make sense in context of the working procedures at Groote Schuur Hospital. A minority of respondents had ever consulted a psychiatrist, psychotherapist or counsellor, and just as few had ever attended a coping skills course or a type of support group. The reported utilisation of support groups was, in fact, substantially lower than the levels found in the United States by De Bocanegra (1992) and Taylor, Falke, Shoptaw, &

Lichtman (1986). These result thus affirm the earlier noted low utilisation of CANSA's Cancer Care and Resource Centre, and acknowledges the frustrations felt by the providers of such services.

More significant proportions of the sample did report contact with a social worker and/or a visit from a veteran patient. Distressed scoring respondents, in particular, appeared to have had some contact with a social worker. It is probable, however, that the high reported contact with a social worker reflects standard referral practices in the oncology clinics, whereby doctors refer emotionally distressed patients to the department social worker (Berard, 1995). With regard to veteran patient visits, a CANSA affiliated breast cancer patient organisation (Reach-for-Recovery) attempts to visit most newly diagnosed breast cancer patients. In either case, therefore, one cannot presume that respondents themselves actually sought out such services.

The background literature on the utilisation of psychosocial services has suggested several explanations for the reported utilisation trends. In the first place, it has been suggested that people might want to utilise psychosocial services but cannot do so due to various practical reasons such as transport costs and time constraints. For most psychosocial services, however, the present results do not support such an hypothesis. Reported interest in psychosocial services among our sample was scarcely higher than reported utilisation of psychosocial services. For example, not more than 3% of the sample showed a decisive 'strong' interest in consulting a psychiatrist or a psychologist/counsellor. 'Strong' interest in a coping skills course and most strikingly, a consultation with a social worker, was also no higher than 15%. This lack of reported interest in a social worker affirms the suspicion that people are referred on to the social worker by their doctor or other authority figure. In other words, it is apparent that a large proportion of respondents who had consulted a social worker did not do so out of their own accord.

A reasonable amount of interest was however expressed for the various types of support groups (40-50% of the sample showing at least 'some' interest for self-help groups and informal gatherings), and an even broader interest was expressed in veteran patient visits (close to 70% of the total sample showing some interest). This lends support to Chesler's (1991, 1993) argument that less professionalised and pathology orientated services could be more appealing to people with cancer. It is particularly noteworthy in this regard, that the most professionalised services such as psychiatry and psychotherapy/ counselling attracted the least interest, less professionalised services such as coping skills courses and professionally run support groups (in the sense that some use is made of fellow patient support) attracted somewhat more interest, and the least professionalised services such as self-help groups and veteran patient visits (with no professional involvement) attracting the most interest. The generally positive attitudes expressed towards the concept of fellow patient support testify to the above observations.

By comparing respondents who expressed an interest in the types of psychosocial services versus those who expressed no interest, several tentative conclusions could be drawn. In the first place, respondents who expressed an interest in any of the services, were, on average, younger than those expressing no such interest. This result was consistently obtained for nearly each type of psychosocial service, suggesting that the older the person with cancer, the less likely it is he or she will seek out psychosocial help, regardless of the particular type of service. Psychosocial care is a relatively new phenomenon, and it could therefore be expected that older people have never utilised such services in previous life-crises. When diagnosed with cancer such people probably utilise the social support and coping resources they have always used in the past (e.g. family, religion, church fellows).

For most types of psychosocial services, respondents expressing an interest in the service scored, on average, higher on the psychological morbidity scales (particularly the HADS: anxiety sub-scale). It appears, therefore, that a substantial number of respondents were aware that they were psychologically distressed and that they could thus potentially benefit from some form of psychosocial care. Only with regard to informal gatherings and to some extent social work did psychological distress appear unrelated. In other words, although a substantial number of respondents expressed an interest in informal gatherings, this interest did not seem to depend on whether the respondent was feeling distressed or not. Respondents could, therefore, regard informal gatherings and perhaps to some extent social work as separate and distinct types of services. Whereas services such as psychiatry, professional support groups, and coping skills courses are probably regarded as 'psychosocial treatment' services of some sort, dealing with *emotional and psychological* concerns, social work and informal gatherings could be regarded as different types of services. Social work could, for example, be perceived to be a 'practical' service, attending to disability grants and associated problems instead of emotional concerns. Informal gatherings, although appealing, could be regarded as just that; 'informal gatherings' - a potentially pleasing, but nevertheless ordinary social interaction (as opposed to a 'therapeutic' interaction).

The social support data provided weak but nevertheless interesting results. Respondents interested in psychiatry, psychotherapy/counselling, and self-help groups were, on average, less satisfied with the support and understanding received from their doctor, compared to respondents who expressed no such interest. One could speculate in this regard, that psychiatrists and psychologists could somehow be regarded as 'alternative' professional health care workers - a substitute 'doctor' who will attend to one's emotional issues. Self-help groups, at the other end, obviously offer something else. Here one could speculate that some respondents regard the self-help group as an opportunity to unload their concerns - and dissatisfactions with medical care - without the threatening presence or interference of 'professionals.'

Respondents expressing an interest in coping skills courses, professional support groups, and informal gatherings, were, on average, less satisfied with the support and understanding received from their family, compared to respondents expressing no such interest. For some respondents, therefore, these services could be regarded as potential social support resources - as potential substitutes to the support received from one's family. It was argued above that some distinctions could be made between services dealing with emotional problems (e.g. psychiatry, professional support group), practical concerns (social work), and pure social entertainment (informal gatherings). The above results pertaining to social support suggest some further functional distinctions between the various psychosocial services. It appears in this regard, that respondents differentiated to some extent between the provision of professional expertise/advice on the one hand and the provision of social support on the other. This is in accordance with Rose's (1990) findings that people differentiate between emotional and instrumental (information, clarification) functions of support.

The present results did not rule out the possibility that different types of psychosocial services could appeal to different types of people. By comparing respondents on various demographic variables, some tentative hypothesis could be put forward. Psychotherapy and counselling, for example, appealed to more high earning status respondents and fewer low earning status respondents than expected. Social work, on the other hand, appeared to appeal to more low earning status respondents than expected. The variable 'earning status' was not statistically relevant, however, to the level of interest observed in the various support groups and a coping course. More high earning status respondents than expected did express an interest in veteran patient visits. Such are flimsy results, however, and are of little help to the present study aims.

Although respondents expressing an interest in psychosocial care were, on average, more psychologically distressed than those not interested, this gave us little indication as to the proportion of psychologically distressed respondents expressing no interest in psychosocial services. Furthermore, no indication was given regarding the comparative appeal of the various psychosocial services among the psychologically distressed scoring sub-sample. Although prevention certainly is a worthwhile goal, the whole reason behind the system of psychosocial care is the presence of psychological distress among people with cancer. Psychologically distressed people with cancer are, therefore, ultimately the primary target market of a system of psychosocial care, and as a result the utilisation and interest trends among this sub-sample needed to be examined.

The results of this secondary analysis were quite disconcerting. Although respondents expressing an interest in psychiatry scored, *on average*, more distressed than those not interested, it was striking to note that none of the psychologically distressed scoring respondents expressed a *strong* and decisive interest in seeking out the services of a psychiatrist. The level of interest expressed in psychiatry among the psychologically distressed scoring sub-sample was, in fact, only marginally higher to the level of interest expressed in the total sample. With the exception of self-help groups and veteran patient visits, such was the case for each type of psychosocial service. For example, only about 20% of the total sample expressed an interest in a coping skills course. Among the psychologically distressed scoring sub-sample however, still no more than 30-35% expressed an interest in a coping skills course, with less than 15% expressing a strong interest. Similarly with regard to both professional support groups and informal gatherings, less than 20% of the distressed scoring sample expressed a strong interest. Self-help groups and veteran patient visits, however, managed to appeal to a large proportion of the distressed scoring sample. Not only did a substantial number of respondents express a strong interest in this service, but the proportions of interested respondents in this sample, were also substantially higher to those observed in the total sample. By comparing the levels of interest in the various psychosocial services it was clearly evident that self-help groups and veteran patients appealed both broadly and powerfully to the psychologically distressed scoring sub-sample of respondents.

The present survey has elicited several interesting trends, and has certainly indicated what a more appealing and consumer-friendly system of psychosocial care might look like. Such information is ultimately not enough, however, if informed decisions pertaining to a system of psychosocial care are to be made. To fulfil this task, the results need to be supported by a thorough understanding of the reasons lying behind the obtained trends. The survey has, in this regard, provided us with some limited clues. The relatively strong interest in veteran patient visits and self-help groups, for example, was to be expected considering the positive attitudes expressed toward the concept of fellow patient support. This theme was affirmed by the poor appeal of the most professionalised services and the contrasting high appeal of the least professionalised services. ‘Professionalised’ here implies the involvement of a professional or expert, as opposed to the involvement of fellow patient/s. The relationship was however not that straightforward, since respondents appeared to make some functional distinctions between the various services. For example, both self-help groups and informal gatherings are non-professionalised services, and interest in such services was thus expectedly high. Informal gatherings, however, differed to self-help groups in two manners: respondents expressing an interest in self-help groups were more distressed to those expressing no such interest, and were less satisfied with the understanding and support received from their doctor. Those expressing an interest in informal gatherings, on the other hand, were *not* more distressed to those expressing no such interest, but were less satisfied with the understanding and support received from their *family*. It could be argued, therefore, that those distinctions have something to do with the relatively high appeal of self-help groups compared to the somewhat lower appeal of informal gatherings, even though informal gatherings must be the least professionalised service conceivable.

One could speculate that the difference revolves around the distinction between instrumental and emotional functions. Perhaps self-help groups and patient visits are still regarded as having instrumental functions, since fellow patients - as ‘experts’ on the cancer experience - relate to one another within a certain instrumental structure or frame (the ‘group’, the ‘visit’). Informal gatherings, on the other hand, could be regarded as a potential source of emotional support; the type of support one might receive from one’s family, or more aptly, one’s friends. An area of blatant speculation has been entered, however, and still no real progress has been made in answering the range of ‘why’ questions. If anything, more of such questions appear the further we speculate.

Why should there be a difference between instrumental support and emotional support, and what exactly is meant by those terms? If both psychotherapy/counselling and self-help groups have instrumental functions - i.e. they are both to some extent problem-focused - why then is their relative appeal so contrasting? How do respondents make sense of their lives and pain, and how does it influence their attitudes towards the various psychosocial services? And perhaps at the root of it all; why do respondents reject more professionalised services, and why are they so positively inclined toward the concept of fellow patient support?

The qualitative sections of the questionnaire were of little help in answering the above type of questions. A large proportion of respondents did not provide any commentary, and the commentary that was received varied so drastically and furthermore was so superficial that it really was of little use. More in-depth discussion will be required to gain insight into respondents' reasoning and attitudes. The responses pertaining to fellow patient support were more interesting, however, with relatively consistent results being obtained in this regard. Sharing experiences and fears, and taking comfort from the fact that others experience similar feelings appeared to be both the main reasons why respondents felt psychosocial care could possibly be of help, and why fellow patients could help each other. Practical help, and general encouragement and moral support were also frequently mentioned. These results thus once again affirm the central role of fellow patient support, and provide at least some idea as to why respondents feel so positively inclined toward such forms of support. Nevertheless, the questioning can continue; e.g. why is it that sharing experiences with other people in similar situations is potentially comforting?

If a truly efficient and consumer-friendly system of care is to be established, which is firmly based on a genuine understanding of the person with cancer, then such questions need to be answered. Such questions can only be answered by entering into dialogue with the person with cancer. It is clear, however, that the trend-eliciting questionnaire survey is an unsatisfactory form of dialogue. Patterns and trends are not enough; we need to know why such patterns or trends exist. In order to accomplish this task it is best we turn to qualitative research.

9. QUALITATIVE RESEARCH: GETTING TO KNOW THE 'SUBJECT'

Improvements in clinical medicine have, ironically so, played a large role in the emerging proliferance of chronic illness. Previously fatal illnesses are more often open to treatments which offer the possibility of extended life-span. As a result, there exists now a growing population of seriously ill people requiring frequent and sometimes continuous care. Psychosocial oncology and its associated disciplines are largely a response to this phenomenon, prompting the scientific investigation of the patient's quality of life, level of psychological distress, social support sources, coping behaviours, and other so-called psychosocial issues. Such disciplines have, however, attempted to apply the research methodologies of their medical counterparts. For example, Holland (1992) in a recent review of psychosocial oncology, identifies the field as a 'sub-speciality' of oncology. In this regard it has placed the focus on experimental investigation and the search for 'objective' knowledge (Redd, 1995).

Concurrently to the increasing interest in psychosocial oncology, social science in general has witnessed a renewed interest in qualitative research. Critical reconsideration of traditional scientific models, and an increasing recognition of the historical and social foundations of knowledge, have led, in this regard, to what in the United States is called the 'interpretative turn' (Saillant, 1989). With regard to chronic illness, the interpretative approach has been applied mainly by medical sociologists and anthropologists (e.g. Anderson, Blue, & Lau, 1991; Charmaz, 1990; Gerhardt, 1990; Jackson, 1994; Kleinman, 1988; Mattingly & Garro, 1994; Robinson, 1990; Saillant, 1989; Sontag, 1978). Some of the primary motivations behind the qualitative approach is that it sheds light both on the *subjective* illness experience (Conrad, 1987; Gerhardt, 1990; Strauss, 1990), and the *social* or cultural context of illness (Kleinman, 1988; Saillant, 1989). Instead of attempting to identify the variables associated with (or even better: the variables causing...) psychological distress or interest in psychosocial care, the qualitative approach is interested in providing 'authentic' data (Gerhardt. 1990), i.e. describing the experiential side of how the illness and its treatment affect a person and his or her family. From an 'insider's perspective' we cannot necessarily talk about variables such as 'psychological morbidity', 'social support', and 'coping styles' because such are not necessarily the terms in which the patient experiences his or her life. The qualitative approach suspends judgement on the exact meaning of these terms, and simply put, asks the patient him or herself why psychosocial care is - or is not - appealing.

As is probably already clear to the reader, the issue here is not simply a matter of methodology. On the contrary, it is about paradigms and meta-theory, about how we conceptualise our subject matter before we even start doing the actual research. It is argued, in other words, that any 'scientific' method caries with it a particular conceptual structure through which we come to understand reality and the subject. Do we understand the behaviour, thoughts, and feelings of the patient as emanating from natural and universal laws of nature, as Redd (1995) understands the anticipatory side effects of cancer chemotherapy? Or do we understand the patient's behaviour and well-being in terms of relatively stable personality factors, as Watson et al. (1988) understand people with cancer's coping behaviour. Or, do we follow Saillant (1989) and understand the person with cancer as a sociohistorically contextualised being, whose experience takes shape by and through the broader cultural and historical meaning systems?

As has been reviewed in chapter 1, psychosocial oncology has certainly benefited from the first two approaches illustrated above. People with cancer undoubtedly experience various forms of psychological distress, and numerous psychosocial interventions are indisputably effective in alleviating such psychological distress. They have, however, not helped in persuading people with cancer to make use of such services. This lack of interest in psychosocial care is as of yet a largely unacknowledged problem, which nevertheless is capable of challenging the very validity and relevance of the discipline. As pointed out earlier, what is the point of channeling scarce resources into unwanted services, and do we really understand what is going on if we cannot even convince the 'victims' themselves to make use of our services?

An alternative approach is thus required, one which not only provides insight into the illness experience, but is also explicit and inquiring about how the illness experience takes shape. It is in this regard that simply proceeding ahead with a 'qualitative approach' is not enough. Too many variants of such qualitative approaches exist, and too many such studies in the past have not bothered to outline what exactly they mean with qualitative research, the nature of their subject matter, and on what basis they interpreted their results. The next chapter, therefore, will serve as a relatively exhaustive theoretical introduction to the empirical work conducted in chapter 5. Chapter 4 will serve a further function, however, concerned more broadly with the status of psychosocial oncology as a science. As already argued for, the level of self-consciousness within the field, particularly with regard to the various methodological and practical problems it is experiencing, is astounding (Frank, 1991). Psychosocial oncology is vulnerable to - and in need of - a comprehensive metatheoretical critique, a critique which has already made its presence felt in other areas of social research (see Billig, 1987; Danziger, 1990; Gergen, 1985; Harre, 1983; Parker, 1989, 1992; Potter & Wetherell, 1987; Rose, 1990; Sampson, 1989, 1993). Chapter 4 will thus serve as such a metatheoretical critique, and set a tone for the entire thesis. At one level, this thesis is concerned with a very practical problem: i.e. why people with cancer resist psychosocial care. At another level, however, this thesis is a critique of psychosocial oncology: it places the spotlight on a rather embarrassing practical 'hassle', and it problematises certain metatheoretical assumptions underpinning the discipline.

CHAPTER 4

THE SELF: NARRATIVE AND DISCOURSE

1. INTRODUCTION

Essentially, this thesis is concerned with two 'objects': the person with cancer and his or her experience; and the system of psychosocial care aimed at improving the quality of this experience. These two 'objects' can be further untangled however. In one sense it is reasonable to talk about the 'actual' person with cancer and his or her experiences, and the 'actual' system of psychosocial care, as they exist in the world 'out there'. As researchers, however, we do not have direct access to these 'natural objects,' but deal instead with artefacts (Danziger, 1990): test scores, rating scale scores, questionnaire results, interview results, statistical distributions, etc. Using such data we then construct theoretical models which manifest practically as journal articles, books, lectures, etc. We can, in other words, quite reasonably make a distinction between the 'actual' person with cancer, and the 'theoretical' literature describing him or her. The 'actual' person with cancer is the person 'out there' who feels, acts, talks, and suffers, and the 'theoretical' person with cancer is the image we read about in journals and books, and hear about in seminars and lectures. The aim of science, of course, is to make sure that theory mirrors reality.

In more recent years, however, this epistemological distinction has been the object of intense debate in nearly all disciplines in the humanities. From these debates a framework has emerged which argues that both the person with cancer, and the theoretical body describing him or her, are at least to some extent sociohistorically constituted. The sociology of knowledge, in this regard, has illustrated how the artefacts (figures, tables, etc.) we find in journals are not raw flashes of 'nature', but are determined largely by a variety of changing social microprocesses (e.g. Danziger, 1990, 1993; Diesing, 1991; Latour & Woolgar, 1979). Not only is psychological knowledge socially constructed in this regard, but according to Danziger (1990), even the essential 'nature' of the subject has been historically constructed in particular ways so that science is made at all possible. The research participants, in this regard, emerge as universal and ahistorical 'subjects', reacting only to the dead materials presented to them. The social context in which investigative practice takes place, from the experimental situation to the broader professional environment, has been shown to influence what is researched, how it is researched, and in what form the eventual theoretical image emerges (Danziger, 1990, 1993).

Other authors have also at a more macro-level illustrated how the 'theoretical' subject is historically rooted in particular philosophical and cultural metaphors. Hermans & Kempen (1994) and Potter & Wetherell (1987) explain, for example, how the modern 'theoretical' subject is rooted in Rene Descartes' encapsulated *cogito* (rational, unified, and potentially self-knowing subject). With regard to psychosocial oncology, Frank (1990) has argued along similar lines that the discipline has to an extent produced (rather than revealed) particular images of what the 'normal' and 'adaptive' psychological response to cancer should be. For example, the patient imbued with 'fighting spirit' and a strong sense of personal control (who bears a striking resemblance to the morally prized Western individualist) is frequently presented as the 'healthy' and 'adaptive' coper.

From a different perspective, an increasing body of work has begun to explore the ways in which the 'actual' subject is constructed through narrative and discourse; or more specifically, how we, as ordinary people, make sense of ourselves using narrative and discourse (e.g. Hermans & Kempen, 1994; Parker, 1992; Potter & Wetherell, 1987). Such authors claim that there is no 'deep' or unified self to be uncovered using research and therapy, but that on the contrary, we as ordinary people 'construct' multiple and dynamic selves using the broader patterns of language available to us, patterns which are in turn sociohistorically embedded. According to this understanding, the person with cancer who copes with 'fighting spirit' is not simply acting out an ingrained personality trait, but has discursively 'constructed' him- or herself using a 'fighting spirit' discourse.

The implications of the above understandings are obviously huge, in that it collapses the rather straightforward idea that science attempts to describe accurately a 'given' (and essentially stable) reality 'out there'. On the contrary, the argument is put forward that the theoretical image of the 'subject' is not a direct representation of 'nature' but is at least partly determined by the socio-historical context within which the research takes place (from the specific characteristics of the experimental situation to the broader metatheoretical framework). The situation is further complicated by the suggestion that the actual subject, we as social beings, make sense of our worlds and ourselves using various understandings implicit in language ('discourses'). By accessing a variety of such discourses in differing contexts, it is thus argued that a person can have multiple (and sometimes contradictory) selves. The relationship between the actual person and the theoretical body describing him or her therefore runs in two directions. Theory can 'mirror' differing and contrasting selves, selves which in turn could be informed at least partly by existing psychological theories (e.g. the humanistic self versus the psychodynamic self, in turn informed by the popularisation of humanist and psychodynamic theory in lay literature). This is not to say, however, that people are 'docile', passively accepting various versions of the world and self. On the contrary, a primary point of this thesis is that people can and do resist certain 'inscriptions' (Fox, 1990; Parker, 1992). Tensions between, and within various 'discourses' enable argumentation and dialogue (Billig et al., 1988; Hermans & Kempen, 1994), which in turn can serve as platforms for resistance. For our purposes, it is therefore hypothesised that people with cancer resist various aspects of the discourses weaving through psychosocial oncology and its associated services. In order to understand why they do so we need to talk to people with cancer; asking them why they reject psychosocial services, in context of the sense they have made of their own lives and situation.

Before moving on this largely empirical work, it is necessary to outline in some detail the argument introduced above.

2. THE CONSTRUCTION OF THE THEORETICAL SUBJECT

Since the last two decades or so, an increasing number of sociological studies have focused on the practice of science (e.g. Danziger, 1990, 1993; Diesing, 1991; Latour & Woolgar, 1979), arguing and illustrating that such practice is primarily a social activity, and thus depends on a host of precariously balanced social relationships and structures. Focusing specifically on the discipline of psychology, Danziger's (1990) work has been hailed by some commentators (Stam, 1992) as the most important analysis of psychology's history to date. For one, it is a highly rigorous historical examination of 20th century psychological experimentation, using methods familiar to scientists. On the other hand, however, it clearly exposes the problematic metatheoretical issues in psychology from 'within' (as Rorty, 1980, has accomplished in philosophy), in a sense 'proving' their relevance. By illustrating how the most significant changes in the investigative practice of psychology lay not in improvements in the means (method), but in changes in the ends (who uses the research?), Danziger (1990) effectively put forward the point that the investigative practice of psychology has been (and still is) shaped by prevailing social forces. Such an argument, in turn, however, puts into question the ontological and epistemological foundations of psychology, which thus justifies a foray into some of the alternative literature (e.g. Gergen, 1985; Parker, 1992; Potter & Wetherell, 1987; Shotter, 1988). First, however, an outline of Danziger's (1990, 1993) findings and arguments:

As discussed earlier, in scientific papers and journals no raw facts of nature are to be found; only elaborately constructed artefacts (graphs, tables, statistical trends, etc.). These artefacts are produced according to explicit rational schemes accepted within a certain community of investigators. Such schemes not only provide a framework for the interpretation of data, but also involve the practical rules for the production of that data (i.e. how to do a psychological experiment). Danziger's point here is that these rules are not just logical or technical details, but involve both the immediate and broader social context. The researcher, in this regard, needs to take into consideration the expectations of the professional environment (as to what counts as valid and relevant knowledge), the expectations of the broader social milieu (the 'practical' use of knowledge), and the expectations of the research 'subject' (how to go about 'doing research'). As Danziger (1990) shows, however, such socially embedded 'constructive schemes' (as he calls them) have undergone historical changes in response to various broad social and political forces.

Rather than a single rational and progressive development in scientific method, Danziger showed how during the 20th century, three different models (the Wundtian, the Galtonian, and the clinical experiment) strove to define the nature of psychological investigation. Each one advocated a different scientific method, had different professional interests, and competed for different audiences (markets). It was the Galtonian model, however, based on the statistical elucidation of individual differences, which finally came to dominate modern psychology. Statistical methods allowed the 'lifting' out of particular attributes of a 'constructed collective subject' (e.g. I.Q.), which in turn facilitated the grading and sorting of individuals according to such aggregated norms. Danziger's argument, however, is that this model came to dominate psychology not because it was intrinsically more scientific, but because it managed to appeal to broader interest groups. Educational and military administrators, in this regard, played a prominent role in the development of Galtonian psychology, since such psychological knowledge allowed the rationalisation of institutional practice (i.e. increased efficiency and 'rational' justification). Scientific and professional status was furthermore guaranteed through the 'mystique of numbers' (i.e. a statistical system - not invented by psychologists), and the 'discovery' of individual differences (i.e. 'underlying' continuous dimensions which remain identical for all individuals).

Danziger (1990) has made the further point that part of the justification for knowledge claims depend on a particular construction of the 'subject.' With regard to the psychological experiment, therefore, the reason a primarily contextual, individual, and social interaction is capable of eliciting 'universal', 'objective,' and 'ahistorical' knowledge, depends at least partly on the identification of the research participants as 'experimental subjects.' In other words, the universal 'subject'ness of participants is emphasised over and above their personal and social identities and histories. The various kinds of hardware and software (test materials, apparatus, etc.) and the particular social structure of the psychological experiment, in this regard, allowed investigators to overlook the social character of these situations. Statistical methods, for example, facilitated the 'prying' loose of people from the social context in which they live. Human behaviour would thus be regarded as the product of the properties of abstract and socially isolated individuals ('subjects'). Although in recent years there has been some acknowledgement of the social element (e.g. 'experimenter expectancy effects', 'demand characteristics'), Danziger (1990) points out that such conceptualisations are more psychological than social. Research might show that such influences exist (and attempt to measure them), but does not strive to understand the social forces and processes involved in the production of these effects. Instead of viewing the psychological experiment as essentially a social interaction, investigators assume that 'contaminating' social influences can be 'corrected' for. In other words, the status of the psychological experiment as a route to the 'natural object' thus remains intact, even though it is prone to 'extraneous' threat.

According to Danziger (1990) human subjects cannot, even if they try to, act 'naturally' in the experimental situation. The point being made here is that the experimental situation primarily is, and depends on, a specific social relationship between researcher and human data source. This social element is not a 'contaminating' variable to be corrected for, but is an essential precondition for the experiment to take place. If the research participants do not co-operate, and abide by the rules defining research, then no scientific psychological study will be possible. Such co-operation is under normal circumstances received, because the psychological experiment has become a social institution recognised by most people with a certain level of education - and thus partially explains why some forms of cross-cultural research are exceptionally difficult[1].

By arguing that psychology's success as a scientific discipline rests on the construction of an ahistorical, socially isolated subject, Danziger (1990, 1993) set the stage for his most radical argument; that psychology is not a neutral science but is decidedly ideological in character. By aligning itself with various administrative social institutions, psychology has accommodated to prevailing ideologies and political prejudices, and through its methodology has presented such 'norms' as somehow 'natural'. Psychology, in other words, is not simply mirroring the individual attributes of human beings, but is reflecting and affirming the (contested and diverse) socio-historical structures which create the 'individual attributes' of human beings.

Danziger's (1990, 1993) work is certainly a convincing acknowledgement of the socially constructed character of psychology, but as Stam (1992) has noted, it leaves open the questions of ontology and epistemology. What, in other words, can we say about psychological realities, and our supposed access to such realities? According to Danziger (1993), observed regularities are socially constructed regularities, and as such can never allow us to infer the independent existence of irreducibly psychological, non-physical, and non-social phenomena (Stam, 1992). Psychological knowledge, in other words, has a highly restricted validity, the boundaries of which most psychological theories overstep (i.e. by saying something 'general', 'essential' or 'natural' about human beings) (Fiske & Shweder, 1986; Nichols, 1993). Differences between psychology and marketing research methods illustrate this point well. By utilising some of the major advances in statistical science, the marketing research industry has been able to claim vast improvements in the predictive power of its research tools (Research International, 1995). Researchers in

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[1] This researcher has also noted, for example, how in health care settings (such as psychosocial oncology) research participants' co-operation is often obtained by (inadvertedly) utilising medical authority. Being addressed by the term "doctor" may be incorrect but it certainly facilitates smooth fieldwork.

psychosocial oncology, likewise, have placed similar emphasis on rigorous methodology and statistical power (e.g. Cella, 1992). Contrary to psychology, however, marketing research aims to obtain social information as rapidly as possible, so that informed marketing decisions can be made timeously. Latest information technology enables research firms to produce relevant information 24-48 hours after being given the order by a client. Such information, therefore, is treated as a product with short 'shelf life', and only applies to the particular population investigated. Psychology, on the other hand, aims to say something more universal and 'theoretical', and thus also takes a great deal more time to produce such statements (many academic research projects will run for at least a year). It is exactly such theoretical statements, however, which fall prey to the above criticisms, since they claim validity beyond the specific time and place of the research situation, or even more problematical, they aim to say something about the essential 'nature' of human beings. With regard to psychosocial oncology, therefore, it is relatively unproblematic to state that anywhere between 10-40% of cancer patients at Groote Schuur hospital experience some form of psychological distress (a straightforward epidemiological 'fact' which says little about the essential nature of human beings), but to argue that a distinctive human personality trait ('fighting spirit') causes better psychological 'adjustment' to stress is significantly more precarious (since it says something about the essential nature of human beings: - that 'personality traits' exist, that a trait identified as 'fighting spirit' exists to varying degrees in all people, etc.).

This type of critique gains further weight when the contrasts between various paradigms in psychology are examined. Several commentators have noted, in this regard, how psychology has failed to institute a single unified paradigm informing methodology, epistemology, and ontology (i.e. the essential nature or 'reality' of the subject - e.g. psychodynamics versus cognitive science) (Fiske & Schweder, 1987; Nicols, 1993). Instead of selecting one framework as the 'correct' one and rejecting the others, however, there appears to be a growing realisation that most models have at least something to say about the human subject. In other words, most models do 'mirror' to some extent what is going on, even though they may be in contradiction to each other.

Danziger's work thus ultimately leaves us with some thorny metatheoretical issues. If psychological knowledge is socially constructed then what could we possibly say about a reality independent of the methods used to access it (i.e. the question of ontology). Secondly, if we do come up with some sort of ontology, then what criteria or standards do we have left to evaluate the validity of our knowledge claims (i.e. the question of epistemology). With regard to psychosocial oncology, therefore, how can we tell whether our theoretical knowledge regarding the person with cancer is an accurate reflection of 'reality'? The above arguments suggest that our theoretical models of the person with cancer might be more the product of our sociohistorically embedded 'constructive schemes' than a 'flash of nature'. In other words, the methods of psychosocial oncology produce a very particular image of the person with cancer: an image marked by concepts such as 'psychological morbidity', 'social support', 'coping styles / strategies', 'psychological adaptation', and 'psychosocial intervention' or 'care'. The latter concept, which is the focus of this study, thus logically follows from the other concepts. If lack of 'social support' and 'unadaptive coping strategies' cause 'poor psychosocial adaptation' then it follows that a 'coping skills course' and a 'support group' could be useful and appropriate interventions. We have seen in chapters 2 and 3, however, that people with cancer themselves might not agree with this logic. The present chapter draws further attention to this discrepancy by arguing that social and psychological reality may not be what psychosocial methods tell us it is. People with cancer might make sense of their situation in a very different manner, resulting in a rejection of the available psychosocial services. Two questions therefore stand before us:

- *Ontology*. What can we say about people with cancer (or people in general) before we begin with research?
- *Epistemology*. Once we have said something about the nature of reality, how do we go about researching it?

In his review of Danziger's (1993) book, Stam (1992) quite rightly directs us to a rapidly expanding body of work which places the focus squarely on language and conversation (Harre, 1983; Hermans & Kempen, 1994; Parker, 1992; Potter & Wetherell, 1987; Shotter, 1988; Wittgenstein, 1958). The ontology of social constructionism, in this regard, is not a reality of things and structures but of 'persons in conversation' (Harre, 1983, p.20, from Stam, 1992, p. 632). If we have difficulty talking about psychological things and structures then what we can do is examine the talk describing psychological things and structures.

3. THE TURN TO LANGUAGE

Over the last two decades or so, various alternative approaches to the above discussed problems have been proposed, which have in common an emphasis on the socially constitutive power of language. The turn to language has developed under an array of different banners, however, with social constructionism, post-structuralism, post-modernism, and discourse analysis being just a few. To begin to make sense of this approach it is useful to start at the micro level; the analysis of meaning; and to progress to the broader implications from that philosophical base. The work of Ludwig Wittgenstein will be drawn on in this regard, partly because of the prominent role his work has played in the development of the language orientated approach, but also because his work embodies the move from a representational epistemology to a social epistemology, and is thus highly illustrative.

Toward a social epistemology: Ludwig Wittgenstein

In line with the logical positivist movement, philosophers such as Bertrand Russel, Rudolf Carnap, and the early Wittgenstein initiated a task to perfect the representational system of knowledge. This early philosophical turn to language shifted the focus from Cartesian representations in the mind [2] to the supposed logical structure of language. Sifting through the mess of everyday language, a logical 'core' network had to be found which perfectly represented the logical and natural order of things out there in the world. The meaning of a scientific word or concept could thus *logically* be derived in its entirety from whatever it represented in the 'objective' world. In this way the practice of science could be cleaned up considerably by ridding itself of all 'vague' everyday type talk.

Years after he stated that the world is the totality of facts, however, Wittgenstein (1958) came to see the representational view of language as not only over-simplified but perhaps also simply wrong. Using several detailed examples, he illustrated how our 'understanding' of the world is not a direct and logical deduction of observation, but is markedly constrained by linguistic convention. Thus rejecting the idea that the entire meaning of a proposition lies in its empirical content (and is thus fixed by a 'factual' state of affairs), he proceeded to the argument that language is used by people as a social tool, and that the meaning of words and phrases thus lie essentially in their use. We can only understand the meaning of a proposition if we have learned the rules governing the use of that proposition. Such rules, according to Wittgenstein (see his celebrated 'private language argument', 1958), can only be learned if we participate in a particular 'language game' or 'form of life', i.e. live in a society of other human beings. Therefore, there is no logical or stable mind-world link providing individual and static meanings. Rather, the meaning of a proposition or word is flexible, dynamic, and practical; it is the result of the prevalent 'forms of life' and 'language games' in society, and as a result can only be understood *within* such 'language games' and 'forms of life.' Meaning is thus essentially indeterminate, being 'socially constructed' as we use language.

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[2] Traditional epistemology concerned itself with the Cartesian relationship between mind and body, or subject and object. A central task of philosophy, in this regard, was to construct a foundatory system for science which would encompass the criteria determining what counts as knowledge. Such an approach never succeeded, however, since simply put, one can never escape the 'subjective' nature of subjectivity - i.e. how can we ever claim with certainty that a 'representation' in the mind accurately mirrors something 'out there' in the real world?

The basic point taken from this work, as expanded upon by other commentators in the social sciences (e.g. Gergen, 1985; Harre, 1983; Parker, 1992; Potter & Wetherell, 1987; Sarbin, 1986; Shotter, 1988) is that social science and theory does not reflect or map reality in any direct or decontextualised manner. On the contrary, our knowledge of the social world (and ourselves), according to these authors, is *socially* 'constructed' through the constitutive power of language (discourse, narrative), since the very possibility of language depends on it being embedded in a society of language users.

A rapidly increasing number of studies have explored these notions in further detail, and have vividly illustrated how even the most 'natural' concepts (e.g. child, self) have varied historically and culturally (and thus appear to be socio-historical artefacts as opposed to obviously 'natural' objects) (see Gergen, 1985, for a review). As discussed earlier, expanding work in the sociology of knowledge and science has also revealed how the criteria determining what counts as knowledge (or fact) not only vary historically, but also appear to depend on a subtle but powerful array of social microprocesses (Danziger, 1990, 1993; Diesing, 1991; Latour, 1987). Taking the view that social knowledge is thus largely negotiated through social interchange (as opposed to a thrusting upon us by 'nature'), further study has examined the broader social implications of affirming particular 'constructions' of the social world (especially with regard to gender and 'race'; see Hollway, 1989; Parker, 1992; Potter & Wetherell, 1987).

In the discussion above, I have described, and attempted to argue for a social epistemology. The argument was put forward that psychology is not able to reflect an independent reality existing beyond the methods used to 'uncover' it. At base of this argument lies an alternative theory of meaning. Instead of adhering to a Cartesian world where meaning exists either in the mind (as a subjective 'idea') or in the material world (as an ontological fact), the argument is instead proposed that meaning is produced or 'constructed' through the dynamic interchange between 'subject' and 'object'. In other words, meaning is constructed by language-using social beings as they go along their business in the world. The person with cancer, therefore, is not simply the holder of a 'subjective perspective' of his or her situation, but is actively constructing a reality as he or she interacts with the world through language. Further questions must be addressed however. If meaning is dynamic and contextual, constructed as we speak, how do we avoid plunging into a relativistic and fluid world where real communication is impossible? And secondly, what of the human subject; how do we make sense of who we are if meaning is constructed as we speak?

In psychology two broad approaches to these questions have made their presence felt. What distinguishes them is their differing conceptualisations of the dynamics of meaning construction. One puts emphasis on the role of narrative and metaphor; the other on the role of discourse and power. Both approaches will be discussed because both are of relevance to our understanding of how the cancer experience is constructed.

4. THE NARRATIVE CONSTRUCTION OF THE SELF: METAPHOR

In rejecting the Cartesian legacy of objectivism, several authors (Hermans & Kempen, 1993; Shotter, 1988) have elaborated what may loosely be called a narrative approach (see also Garro, 1994; Jackson, 1994; Mathews, Lannin & Mitchell,1994; Robinson, 1990). At the heart of this approach, lies the concept of 'root metaphor' (Hermans & Kempen, 1993; Sarbin, 1986). Metaphor here is not viewed as a mere ornamental figure of speech, but as an indispensable structure of human understanding by which we can figuratively comprehend our world (Hermans & Kempen, 1993) (hence; *root* metaphor). It is through metaphor that we are able to structure and organise our more abstract understandings of the world[3].

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[3] This notion that understanding requires certain a priori structures has of course been with us since Kant's Critique of Pure Reason. Kant argued that certain innate and thus universal 'a priori' categories enable understanding of the world, thus bridging the contrasting approaches of idealism and empiricism. More recent philosophers such as Michel Foucault do not discount the necessity of such categories, but argue instead that they exist within language, and are thus sociohistorically constructed.

Rorty (1980), for example, has illustrated how almost the entire history of Western philosophy and epistemology from Plato onwards appears to be based on a particular metaphor which conceptualises mind (and language) as a 'mirror of nature'. The work of Wittgenstein (1958) is hailed in this regard as being a decisive break away from such a spatial metaphor, moving toward a language as 'tool-box' metaphor. Hermans & Kempen (1993) likewise move further and review the work of Sarbin (1986) to elucidate the types of metaphors which have been framing psychological theory. Trait theory, in this regard, is described as an example of formism, which stresses the organisation of the environment on the basis of the form of things (e.g. is this individual type C [cancer prone personality traits] or type A?). A mechanistic model describes the world in terms of cause-effect relationships (e.g. variable A ['fighting spirit'] causes variable B ['psychological adaptation'], as mediated by variable C ['social support']). An organic model describes the world in terms of stages of growth or development (e.g. Kubler-Ross's stages of grief).

The root metaphor structuring and informing the narrative position, however, is *contextualism* (Hermans & Kempen, 1993). According to this model, an historical event can only be understood when it is located in the context of time and space. Such an understanding, according to Sarbin (1986) and Hermans & Kempen (1993), describes reality as a contextual and dynamic web of elaborated events, continuously being influenced and restructured by collateral episodes and the actions of multiple agents. Such changes in structure thus imply that the positions occupied by actors also change. History, in this sense, is not a straightforward accumulation of facts and events, but is more like a narrative, in that events are continuously organised and interpreted (and reorganised and reinterpreted) by the very actors playing roles in the events.

This is thus the crux of the narrative approach: the assertion that ordinary people can be likened to historians-novelists, continuously ordering and reordering (narrating and renarrating) the events they consider relevant to their own lives (Hermans & Kempen, 1993). Such life stories are of course never fixed since the story is retold as new experiences are encountered. By reviewing a broad range of research, Hermans & Kempen (1993) illustrate how narrative pervades ordinary life, from the narrative structure of perception and emotion, to the narrative structure of action. Contrary to more traditional approaches which lift emotions away from their situational contexts ('anger' as a psycho-physiological construct), Sarbin (1989) shows, for example, how more sense can be made of an emotion such as anger by interpreting it as a 'rhetorical action'. The emotion in this sense, is interpreted as an attempt by one person to persuade or convince another of the propriety of his or her values and conduct. With regard to the narrative structure of action, Sarbin (1986) has illustrated the so-called 'Quixote principle'. This principle describes the process of identity shaping through the construction of narrative. First the person constructs an identity by identifying with one (or more) characters in particular 'stories' (e.g. from novels and film to gossip and history), and then attempts to validate or affirm this identity in daily life (by enacting such roles). Such an argument can be extended to provide an alternative to other more 'scientific' psychological explanations of action. Instead of conceiving a trait such as 'fighting spirit' (Watson et al., 1988) as a somehow enduring and possibly innate personality trait (located in the 'deep' psychological self) one could argue that some people have a dominant tendency to make sense of their lives using a 'fighting spirit' narrative (i.e. themes of courage and battle located in language and culture).

At base of narrative lies the process of 'emplotment' (Hermans & Kempen, 1993), which is able to transform a purely chronological listing of events into an organised whole. By ordering and highlighting events on the basis of relevance, ascribing psychological motives, and by accessing 'basic' cultural story themes (e.g. tragedy or romance) and sub-themes, the author is able to bring coherence to isolated and fragmented events.

With regard to chronic illness, Kleinman (1988) used his concept of the explanatory model to show how ill people, and the various parties involved (family, professional care-giver), make sense of the illness experience. The signifiers of chronic illness (symptoms) are used to provide explanatory accounts of the disease, accounts which according to Kleinman, are essentially narrative in character. The patient is described as a revisionist historian, narrating and renarrating past events in the light of current changes, interpreting what has happened, and why it has happened, using the particular storyline chosen. Such 'myth making' is a way of making the situation existentially tolerable. In line with the constructionist approach, Kleinman suggested that over time such explanatory models do not merely reflect the illness experience, but do to an extent create it. The personal narratives thus in a sense construct the experience of symptoms and suffering. By analysing several reconvened interviews with breast cancer patients in the Western Cape, Berger (1990) effectively illustrated how people with cancer make sense of their experience using various culturally embedded explanatory models and storylines. Some subjects, for example, used images of pollution and contamination to describe the disease, and causes were looked for in industrial society and unhealthy lifestyles. Others made sense of the disease using supernatural storylines, for example identifying it as 'God's will'. Coping with pain, suffering, and existential issues was also frequently made sense of within religious contexts, conjuring up themes of courage and dignity. The dynamics of this process were highlighted by showing how the patients re-narrated their experience as they encountered new events (e.g. before treatment to after treatment). Perhaps most noteworthy for our purposes, not one of Berger's subjects made sense of their situation using psychological 'talk' (e.g. 'psychological adaptation', 'coping strategies', 'psychotherapy' etc.). For most of her subjects, cancer was a test of 'moral strength' and needed to be faced with 'courage' and 'dignity'.

The narrative approach certainly provides a useful explanation of how meaning is constructed through metaphor and narrative. Metatheoretically, it is in accordance with a social constructionist emphasis on the social embeddedness and 'incompleteness' of meaning and self; and by placing emphasis on the embodied subject, the Cartesian distinction between subject and object is furthermore collapsed. This is not to say, however, that the subject is no more than a product of society and history. On the contrary, a strength of the narrative approach lies in its emphasis on the active subject, who is able to resist and transform his or her world. People make sense of their lives, and perhaps more importantly, make sense of the conflict and frustration in their lives, using metaphorically infused storylines. This is a dynamic process, operating primarily through conversation and dialogue, both with other people and with oneself (thought) (see Billig et al., 1988). By focusing on inter-subjective transactions and practices, the narrative approach thus effectively illustrates the way in which people establish shared, but nevertheless dynamic frameworks of (linguistic) activity. The approach furthermore suggests (and effectively shows) that the self is a decentralised multiplicity of divergent and even opposed characters that are related to one another in a dialogical way (Hermans & Kempen, 1993). This theme will be discussed further in a subsequent section however.

This emphasis on the dialogical microcontext certainly is the strength of the narrative approach, but ironically it is also its weakness. By focusing only on the activities of narrating subjects we are left with the crucial unanswered question of where the metaphors and narratives come from, or rather, how it is that certain metaphors and narratives come to dominate our understanding of the world. Hermans & Kempen (1993) attempt to answer this question by reviewing several analyses of culture, but ultimately only succeed in describing (not really explaining) several 'basic' cultural narratives (e.g. comedy, romance, tragedy). What is missing is a comprehensive attempt at understanding the dynamics of social structure, and the way in which language weaves through such structures and dynamics. For such an analysis we can, however, turn to what may broadly be termed the discursive approach.

5. THE DISCURSIVE CONSTRUCTION OF THE SELF: POWER

Drawing on the work of philosophers such as Ludwig Wittgenstein, Michel Foucault and Jacques Derrida, and social theorists such as Rom Harre, an increasing body of psychological work has begun to provide a discursive understanding of psychological and social phenomena (e.g. Billig et al., 1988; Edwards, 1991; Gergen, 1987; Parker, 1990, 1992; Potter & Wetherell, 1987; Sampson, 1985, 1993; Shotter, 1990; Seidel, 1993). Although in basic agreement with the narrative approach in its focus on the constitutive effects of language, the discursive approach can be said to take a more radical line on the extent of these constitutive effects. Instead of describing a world of sociohistorically embedded beings narrating and re-narrating a given reality, the argument is taken further that even our 'given' reality is thoroughly and totally constituted through discourse. By discourse I refer here to all the practices, institutions, and values that shape our understanding of the world and are reproduced by our continual use of that understanding (Harris, Lea & Foster, 1995). Emphasis is placed, in other words, not so much on the activities of self-narrating agents, but rather on the constitutive power of language. The narrative approach has illustrated how we, as creative agents, impose structure and coherence on our experience through the use of narrative and metaphor. The discursive approach, on the other hand, has been predominantly concerned with the sociohistorical origins of the structures and categories 'embedded' in language, and what implications they have regarding our self-identities and positions in society. Inevitably, therefore, we are drawn into issues concerned with morality and power.

According to Potter & Wetherell (1987), talk is a form of social action, not only in the sense that we give meaning to our actions, but also in the sense that the very objects of our world are constructed through discourse. Through the working of discourse we apply sociohistorically constructed categories to the world, categories which have their origins in 'real' social power structures (Parker, 1992), but also serve to affirm, justify, or 'rationalise' those social structures. Feminist authors, in this regard, have made extensive use of the discursive framework, in exposing how certain apparently 'natural' categories (such as male/ female) are better understood as discursive practices of society, designed to sustain male domination over females (Gatens, 1991; Hollway, 1989, 1991; MacKinnon, 1989; Sampson, 1993). The concept of 'race' has received similar treatment by authors such as Fairchild (1991), Potter & Wetherell (1987) and Zuckerman (1990). Foucault (1977, 1978), perhaps most notably, has surveyed the historical changes in societies' understanding of various forms of deviance (e.g. madness, crime). Our identities, therefore, far from being relatively neutral or unproblematic 'narratives', contain the categories which sustain, justify, - or resist - the very real historical power structures in society. Such a view thus opens the way for a 'politics of identity' (Sampson, 1993) (as opposed to a search for a 'deep' psychological identity).

Foucault's (1977, 1978) approach to power has been a particularly useful contribution to our understanding of the construction of subjectivity and identity. Contrary to more traditional conceptions of power (e.g. Marxist), Foucault (1977, 1978, 1982) has argued that populations in modernity are managed in a far more subtle and relational manner than they were several centuries ago. Whereas previously populations were directly controlled according to principles of sovereignty (e.g. king in monarchy, public torture and executions), now such regulation is accomplished using certain 'disciplinary technologies' which involve processes whereby individuals assume responsibility for exercising control over themselves, through the use of discourse and knowledge (Foucault, 1977, 1978; Parker, 1989). Power, in this sense, is 'always-ready' present (Foucault, 1978, p.92), embracing power-holder and power-subject in dynamic interplays of power and resistance. We construct ourselves using discourses which implicitly position us in particular structures of power. Various minority movements (e.g. blacks, homosexuals) have used this argument, for example, to assert they have been denied 'voice' to determine their own identities (Sampson, 1993). Available discourses (which includes institutionalised knowledge such as psychology), it is argued, have the forms of domination built into the very order of things (i.e. determining what is normal and abnormal, healthy and pathological, natural and unnatural, rational and irrational, etc.).

According to the discursive approach, therefore, we make sense of our world and ourselves using various sociohistorically embedded discourses, which position us in society in particular ways. It is specifically with regard to the construction of the self, that the institution of psychology takes on reflexive relevance. In terms of our approach, psychological models of the self are inevitably culturally and historically contingent, dependent on certain kinds of social practices. What psychology discovers therefore, may not be the timeless, universal characteristics of personhood. Psychology may simply elaborate instead upon the conventional ways in which people are described in this particular society (Parker, 1992). Psychological models of the self therefore, do not necessarily reflect the true nature of the object, but rather our social history.

The discursive approach certainly provides a useful and insightful understanding of the construction of the self, an evaluation affirmed by the rapid development of discourse analysis (see Burman & Parker, 1994; Parker, 1992, for reviews of discourse analytic research). Hermans & Kempen (1993), from a narrative perspective, criticise the discursive approach (or the 'French structuralist' approach as they call it), however, for placing too much emphasis on impersonal sociolinguistic structures and processes. Such an approach, they argue, destroys the self as agent and leaves behind instead a passive product of social forces (Foucault's 'docile subject' or Nietzsche's 'last man'). Certainly this is a primary distinction between the narrative and discursive approach since the self as agent, according to Foucault (1977, 1978), is a feature of disciplinary power - it is a sociohistorically constructed 'illusion' enabling consent to subjection. Nevertheless, the picture is not that one-dimensional, even for Foucault (1977), who argued that points of resistance are inscribed as "irreducibly opposite" in all power relations (in Wilbraham, 1994, p. 12). For one, various discourses compete for hegemony over certain objects and subjects (e.g. Apartheid era 'ethnic group' discourses versus liberatory discourses), and as Billig et al. (1988) convincingly show, inevitable dilemmas strain the coherence of seemingly unified discourses. The point being, therefore, that dilemmas across and within discourses keep us arguing and thinking, processes which in turn give us the potential to reconstruct our world and ourselves. It is at this point that the discursive and narrative approach rejoin, both flowing into a metaphor most eloquently elucidated by Hermans & Kempen (1993): that of the decentred dialogical self.

6. SYNTHESIS: THE DECENTRED AND DIALOGICAL SELF

Although the above two approaches are in some ways quite competitive, they do both emphasise certain basic principles. These principles will be summarised below and describe what we may call the decentred and dialogical self.

The self resides in discourse

Both the narrative and discursive approach have in common an emphasis on the decentralisation of the self. Contrary to the unified Cartesian cogito - a rational centre of experience 'under the skull' - recent work locates the self in language and culture (see C. Taylor, 1989; Giddens, 1991). These approaches shift attention away from the self-as-entity towards the ways and means the self is talked about, how it is theorised about in discourse. Following Harre (1985), the assertion is made that; "to be a self is not be a certain kind of being, but to be in possession of a certain kind of theory" (p. 262). When a person with cancer talks about his or her 'strong heart' and 'positive attitude' towards the situation, this is not purely a manifestation of some characteristic of the person's personality (the 'deep inner self'). On the contrary, the person is making sense of his or her situation by accessing sociohistorically located discourses (e.g. discourses honouring the free and responsible being who is capable of facing a situation with courage and dignity).

Multiplicity and fragmentation: the post-modern condition

Various theories or models of the self exist in the linguistic resources available to us, and as a result the potential of a multitude of selves is open to us. Post-modern theorists in particular have emphasised how the modern self has become a fragmented kaleidoscope of different images (e.g. Denzin, 1992; Frosh, 1991; Gergen, 1991; Lyotard, 1979). Mass media, mass marketing, and the general shrinking of the world (high technology communication, etc.) has led in this regard, to a fragmentation of reality and identity. To illustrate, I was recently confronted by an eloquent example of the 'post-modern condition', in the form of a young woman bowing her head in respect to a traditional Xhosa healer's dance to the spirits of the ancestors, after which she prayed to the Christian God in unison with a Catholic monk, all while firmly grasping her copy of Madonna's biography.

With regard to psychology, different theories of the self therefore become not competing models, but different possible methods of making sense of oneself (Potter & Wetherell, 1987; Parker, 1992). One moment a person may make sense of him- or herself using trait theory and the next using role theory. Psychodynamic theory in particular, has woven itself through culture, positioning people in various ways and providing understandings of the individual which may quite frequently 'work' (Parker, 1992). A person with cancer, for example, may explain in one instance how she strove hard to face her illness with courage and a positive attitude (existential model), but in another instance will describe herself as a person with a 'strong mind' (trait model). Each explanation could, of course, serve a different social function.

Self-regulation: dialogue between different selves

It has been argued that people construct their identities and 'selves' through the use of language. Therefore since there is no 'given' self, people need to learn how to construct a self, a process which quite obviously is related to the development of linguistic skills[4]. Drawing on the work of Lev Vygotsky (1986) and Rom Harre (1979, 1983), various authors in the narrative and discursive approaches (Hermans & Kempen, 1993; Shotter, 1984) have provided such linguistic understandings of the development of the self. Self-experience, according to these authors, is formed as the child learns the grammar of our language and masters linguistic communication. By internalising early mother-child conversation, inner speech develops, which in turn develops into more efficient symbolic thought (Vygotsky, 1986). Children in this way also learn the conversationally acceptable ways of presenting oneself as a person (Harre, 1979; Shotter, 1984). Such credibility - also related to the power to persuade others of whatever one wants them to accept - is only obtained through the use of very particular ways of self-expression. In other words, what works (i.e. is credible and acceptable) in one situation may become ineffective

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[4] Not only the self and identity, but even intellectual functioning appear to depend crucially on the acquisition of linguistic skills. Sacks (1990), for example, reviews riveting evidence in support for these claims.

communication in another. This pressure most of us experience to be credible and accountable thus gives power to certain sociohistorically embedded 'structures' of self-experience. Sampson (1985), for example, has argued that the 'ideal' self in Western culture is a centralised and unified centre of rational experience, which has its environment under reasonable control.

Although we certainly are constrained by the linguistic resources we have available to us, the inherent dilemmas between and across such discursive resources require that we pay some attention to the particular ways in which we present ourselves to the world. In order to do this, however, we need the ability to look at our selves; 'I' need to evaluate and manage 'myself'. It is exactly this grammatical (it is nothing more) split of the person into subject and object which enables us to do this (Harre, 1979; Hermans & Kempen, 1993). By subdividing the self into a public self and a private self; a private 'I' emerges who is aware and can monitor the social 'me', evaluating it as one might comment on the actions of a friend (Hermans & Kempen, 1993). In this way different selves can be created, serving different functions in different situations (e.g. accounting for one's behaviour).

In constructing different selves we access different discursive resources, however, resources which discursively position us in particular ways. In the words of Hermans and Kempen (1993), we thus find ourselves in different, and sometimes contrasting, 'I positions'. Although such 'I positions' are embedded in particular sociohistorical structures and are thus not totally fluid, they are, nonetheless, never fixed life narratives or discourses. Stories are told in particular sociohistorical contexts, and derive their meaning from such contexts. Such discursive contexts are furthermore almost never unified and clear cut (Billig et al., 1988), and as such, a story or narrative never has a fixed meaning, but can be indefinitely re-narrated (see Derrida, 1978). Different I positions therefore inevitably talk to each other; regulating, competing, or even repressing each other, as the person moves through his or her world. The 'courageous' person with cancer, for example, will need keep a check of his or her emotional state and behaviour in order to ensure that no signs of 'giving in' or 'feeling sorry for myself' appear.

Discourse and Power

By placing emphasis only on grammar, however, one is at risk of losing the social dimension of self-discourse. The question will always remain as to why certain kinds of self-constructions and linguistic practices flourish at particular historical periods and in certain societies, only to fall out of use in other periods. Potter & Wetherell (1987), and to a larger extent Parker (1992), answer these questions by examining the social functions of particular self-constructions, and their embeddedness in institutional power structures. In other words, not every interpretation or construction of the self will be acceptable in a specific situation. On the contrary, the methods of conceptualising the self involved in different linguistic practices have serious consequences for the positioning of people in society; they are neither neutral nor arbitrary but produce senses of the self which may be negative, destructive, oppressive, as well as senses which might change and liberate. (Parker, 1992). In a psychotherapist's office, for example, a person with cancer might have trouble maintaining his or her 'courage and dignity' storyline.

Foucault's (1977, 1979) approach (see Parker 1992) demonstrates how the discursive articulation of certain kinds of selves is intimately involved in the reproduction of certain kinds of society. Here people become fixed in position through the range of linguistic practices available to them. The use of a particular organisation of the self not only allows one to warrant and justify one's individual actions (Gergen & Gergen, 1988), it also maintains power relations and patterns of domination and subordination (Parker, 1992). Although such an understanding has been most effectively applied to racism and sexism (e.g. Hollway, 1984), several authors have also critically examined the systems of health care (Young, 1987; Zola, 1975) and mental health care (Burman, 1991; Fairclough, 1992; Levett, 1988). Wilbraham (1994), for example, has illustrated how magazine advice columnists 'medicalize' and 'psychologize' physical attractiveness and monogamy. Such processes, according to Wilbraham (1994), position women in ways which (ironically) perpetuate their subjection. Instead of accepting and advocating deviance, columnists guide their stricken 'patients' toward various medical and psychological 'treatments' which offer a return to 'normality'. With regard to the system of psychosocial care for people with cancer, it can similarly be argued that people's life crisis are 'psychologized', thus transforming them into a form of 'abnormality' or 'pathology' requiring 'treatment'. The discursive approach, therefore, adds an inevitable political dimension to social research, since it aims to elucidate and *critically* analyse various discursive power structures (e.g. sexism, racism, and even psychology).

The mechanics of power thus enable the domination of some self-constructions over others. People's multiple selves may enter into dialogue with each other (Hermans & Kempen, 1993), but quite frequently it may be expected that one particular self-construction could manage to dominate, or even repress, another. It has been argued, for example, that various oppressed social groups (homosexuals, Africans, etc.) have in the past accepted their lot because they were simply denied 'voice' to express their own identity (Sampson, 1995). Homosexuals could have believed that they had 'unnatural' and 'sinful' desires, Africans could have believed that were somehow members of a lesser and thus subordinate 'race', and similarly some people with cancer could believe that they are being punished by God and thus deserve to be stigmatised.

What of the unconscious?

By placing the focus on language and discourse there unfortunately is the tendency to loose touch with that aspect of the self lying beyond words, more specifically, that domain of the self highlighted by psychodynamic theorists; the unconscious. This notion is of relevance to our attempts at understanding the cancer experience because the notion of 'denial', ranging from subtle avoidance to full-blown delusions, has repeatedly entered discussion in psychosocial oncology. Numerous clinicians and researchers have noted, in this regard, that people with cancer frequently 'block' relevant information out of consciousness, a process which very often appears adaptive (Rowland & Holland, 1990). Language orientated theorists such as Jurgen Habermas, Jacques Lacan (as described by

Parker, 1992), Deleuze & Guattari (1972) (as described by Fox, 1992), and more recently Frosh (1991) have incorporated the notion of the unconscious into their work.

Discursive approaches inevitably allow a return to psychodynamic theory. For one, psychodynamic discourses infuse Western discursive practices, and as such, people are able to make some sense of the type of moments when they 'did not know what came over me'. Secondly, and more importantly, the discursive approach focuses our attention on the rather subtle and unnoticed manners in which social forces enter our subjectivities (Frosh, 1991). In attempting to understand the statement 'I don't know what came over me', Hermans & Kempen (1993) drew on psychodynamic theory to elucidate the notion of 'sub-personalities'. According to these conceptualisations, a particular self-construction may be so repressed that it can only reveal itself on occasion in a semi-conscious manner. The basic idea, therefore, is that certain meanings can be pushed into an unconscious realm by a process of 'delinguisticization'. In Habermasian terms, linguistic (and thus conscious) meanings are turned into 'things' (It/Id) (Parker, 1992). *Why* particular meanings are driven into the unconscious is another question we need to turn to. Ego-defence mechanisms, in this regard, are useful explanatory tools but for our purposes need to be understood in discursive terms. We could argue therefore, that contrasting discourses/ self-narratives/ self-constructions attempt to push each other out of 'existence' depending on the particular social context. A person may, for example, push feelings of compassion and associated discursive practices (e.g. love thy enemy) out of awareness when fighting a battle at war. Similarly, it could be expected that a person with cancer is vulnerable to a great deal of such 'repression'. He or she may deny a poor prognosis, and in turn, perhaps in an overly rigid manner, believe that 'the power of the mind' will overcome her illness. In order to make sense of their lives and themselves, people access various historically and institutionally embedded discourses, a process which entails continuous dialogue between different self-constructions, but also inevitably, domination and repression by some over others.

Commentators on modernity have placed particular emphasis on the almost wildly chaotic and fragmented state of current linguistic resources. This post-modern 'crisis' of the self (Frosh, 1991) has been conceptualised in different ways however. For theorists such as Frosh (1991) and Jacques Lacan (in Parker, 1992) the dynamic and largely out-of-awareness multiplicity of the self is an intrinsically problematic state requiring 'illusionary' integration. Psychosis, in these terms, can be regarded as the extreme end of the fragmented self. Deleuze & Guattari (1972), on the other hand, celebrate post-modern fragmentation and multiplicity. For such theorists (see Fox, 1992) a state of dynamic multiplicity is the breeding ground of Desire; the force behind change and the potential to be something other than what one is now. Desire, in this sense, is a positive force enabling resistance to oppressive constructions of the self. Although people may not be aware why they are resisting particular aspects of the world and themselves, for authors like Deleuze & Guattari (1972) and Foucault (see Miller, 1994), such 'blind' resistance is a way out of the delibidinized hell of 'docile' subjectivity. Taking these ideas further, a case could be made for the claim that the forces of Desire in context of the dynamic and multiple self are the very conditions of 'being'; they are what make self and identity at all possible.

Theoretical integration: discursive constraints and rhetorical creativity

Two broad overlapping approaches have been drawn upon to elucidate the manufacturing process of the self. Whereas the narrative approach draws our attention to the creative self-narrating efforts of individuals, the discursive approach warns us to take cognisance of the historically embedded linguistic constraints framing the process of narration. Both points of view depend on each other, however, since it is the practices of narrating individuals which produce and re-produce prevailing material conditions and current social, economic, and ideological systems. On the other hand, the inevitable dilemmas within and across discourses enable (and stimulate) creative dialogue and argumentation, practices which have the power to transform relatively stable discursively constructed selves.

For the purposes of theoretical integration, and as a means of setting the stage for an empirical methodology, some explicit defining of theoretical constructs is in order. I have drawn, in this regard, largely on Harris, Lea, & Foster (1995).

By discourse, I understand in the Foucauldian sense (Harris, Lea, & Foster, 1995; Parker, 1992) the broader social practices, institutions and values that gives language the power to create meaning. Discourses, in this regard, are treated as relatively independent 'objects' of study (Parker, 1992), since individual people *draw on* discourse in varied and creative manners. In people's conversation we therefore do not find entire discourses, only traces of discourse.

The actual language use of speaking individuals can be understood as active argument and thus rhetoric (Billig et al., 1988; Potter & Wetherell, 1987), since in a discursive sense it implicitly or explicitly attempts to account for behaviour (and 'reality'). Although creative and varied, rhetoric nevertheless draws on discourse in patterned ways, and seeks to use the resources of a discourse to define the rules of its argument. Rhetoric, in other words, acts strategically. As a result, it can be expected (and has been illustrated by Harris, Lea, & Foster, 1995; Potter & Wetherell, 1987) that in a particular context people use various 'rhetorical strategies' in patterned ways. In everyday conversation, for example, it is often easy to pick out recurrently used explanations (rhetorical strategies) of salient social problems (e.g. racism), which draw upon particular discourses informing the 'nature' of that problem.

To conclude, this chapter has thus presented a very particular metatheoretical picture of the world. Contrary to a representational epistemology rooted in a Cartesian subject-object distinction, a social epistemology is proposed whereby meaning and language are described as 'constructive' rather than only 'reflective'. A world is described where we as individuals construct our world and our selves using everyday language and rhetoric. We narrate our world and our lives, and in this way make *sense* of our world and lives. The relative stability of meaning and language (and thus 'reality' and self) is explained by the notion of discourse; the broader social, economic, and political 'realities' structuring our lives. A crucial implication of this approach, in particular for our purposes, is that within such discursive social structures we find the social sciences, and more specifically, that body of 'scientific' work describing the person with cancer - psychosocial oncology.

7. PSYCHOSOCIAL ONCOLOGY AND THE PERSON WITH CANCER: WHAT ARE WE TALKING ABOUT?

Psychosocial oncology strives to determine what the psychosocial consequences of cancer are, why and how such consequences come about, and then attempts to design and institute interventions which aim to alleviate any problems. At this level our approach is certainly in agreement with the above aims. The crucial difference arises, however, in the way we conceptualise 'psychosocial consequences' and the way such 'consequences' come about.

In terms of the discursive approach, the psychosocial consequences of cancer are neither 'natural' (stable or unidimensional) psychological reactions, nor are they reactions mediated by personality-based coping strategies. On the contrary, the experience of cancer is discursively constructed by narrating patients, who in turn access broader discourses informing the 'reality' of the cancer experience. Severe physical and emotional reactions may certainly abound, but the meaning attributed to these reactions is constructed by and through the discursive contexts in which such reactions take place. People with cancer may thus draw upon varied and even contrasting discourses to make sense of their situation. By drawing on such discourses, the person with cancer is thus also affirming or reproducing the social 'reality' of such discourses. A person with cancer may read an article honouring the 'courage and dignity' of another patient, and thus attempt to emulate this inspiring image. As the person begins taking pride in his or her courage and dignity, the storyline ceases to be a mere story but becomes 'real.' Similarly, a person with cancer may read a psychodynamic account of a cancer experience, thus teaching the reader about the relevance of emotions, past events, and 'grieving over loss.'

It should now be clear why the discourses of psychosocial oncology (encompassing theory, journals, books, interventions, professional activities, promotional communications, etc.) occupy a more assertive position in the person with cancer's life than might have been expected. The person with cancer is faced with certain discourses informing the reality (or normality) of the cancer experience, discourses which are furthermore strengthened by scientific justifications. Instead of simply reflecting a given reality, the institution serves as a linguistic resource upon which people with cancer can draw to construct their experience. Psychosocial oncology, therefore, far from saying anything essential about the experience of cancer, could simply be recycling the same broader discursive patterns we use to make sense of our lives. For example, Western culture prizes the courageous and dignified individualist, an image most of us attempt to emulate in our daily lives. Psychological research often reflects aspects of this image, links it with 'psychological health' and thus further strengthens the power of Western individualist values (not only are they good traditional values but now they are also 'healthy') (Sampson, 1993, 1995).

Although the above argument problematizes some of the scientific pretensions of psychosocioal oncology, it does not refute the fact that some forms of psychosocial interventions do have the power to ease the pain of having cancer. Furthermore, several discursively orientated authors have emphasised the potential healing power of various psychological interventions (Frosh, 1991; Hermans & Kempen, 1993). Stated simply, it can be argued that various forms of creative dialogue (with a therapist, counsellor, or fellow patient) can enable useful transformations of identity and experience. Although certainly an interesting field of enquiry, this is ultimately not our concern since we first need to convince the intended recipients to make *use* of such potentially useful interventions.

This study seeks to explain why people with cancer resist psychosocial services. In order to accomplish this it is necessary to understand the role of psychosocial care - and its accompanying system of knowledge - in the cancer experience. What does psychosocial oncology offer the person with cancer; not only in terms of services, but more broadly in terms of the discourses it offers, used to construct the 'reality' of the cancer experience? In other words, when we talk about 'psychological adaptation', 'coping styles', and 'psychosocial interventions', what could this mean to the person with cancer? What is it telling him or her about life with cancer and how to deal with it? Do such messages contradict each other, or do they contradict other salient messages the person with cancer has received? In sum, we need to examine how people with cancer discern the various psychosocial services, in context of the sense they make of their own lives and situation.

In order to answer these questions, it is necessary to analyse the everyday rhetoric of people with cancer. How to go about doing this will be addressed in the next section.

8. RESEARCH: DISCOURSE ANALYTIC METHOD

Several proponents of discourse analysis have argued that this methodology should not evolve into one of many empirical 'tools' to be applied to varied topics in an arbitrary manner (Burman, 1991; Parker, 1992; Parker & Burman, 1993; Wilbraham, 1994). Due to its decidedly critical and moral/political character, such authors have argued that discourse analysis should be an end in itself. The aim of a discourse analytic study, in other words, is to perform a critical (and perhaps emancipatory) reading of an existing text. I would not wish to dispute such arguments, and hope that this study, as a critical reading of psychosocial oncology, testifies to that fact. Nevertheless, this study originates from, and is motivated and guided by, an overriding very practical question: Why do people with cancer resist psychosocial services? It is hoped that answers to this question will in turn enable existing structures to improve their services. Since these practical motivations guide this study, it must be acknowledged that discourse analysis is here utilised as a 'tool' of sorts, without, however, losing its critical edge.

It has been argued that in order to make sense of our lives and our world, we draw on shared patterns of meaning rooted in social institutions and structures. Although we refer to such patterns of meaning as 'discourses' (Parker, 1992), they have elsewhere been called interpretative repertoires (Potter & Wetherell, 1987) and ideological dilemmas (Billig et al., 1988). Discourses, as mentioned, are treated here as independent 'objects' of study; they are treated as having a reality independent of the actual talk of individuals, even though such talk draws on, and influences the nature of such discourses. Parker (1992) defines a discourse as a system of statements which construct an object, and qualifies this definition using ten criteria, which serve the additional purpose of informing the actual process of discourse analysis. Drawing on the work of Parker, some defining guidelines for discourse analytic methodology follow:

1. Discourses are relatively coherent and regulated systems of knowledge, practices and power.
2. Discourses are implicated in institutions, e.g. psychology.
3. Discourses shift historically
4. Pieces of discourses are interpretable and analysable within texts (here psychosocial literature, and conversations with people with cancer)
5. Discourses target and construct 'objects' in particular ways, e.g. 'fighting spirit' as a human coping response.
6. Discourses offer individuals subject positions and practices to take up, e.g. strive toward 'adaptive coping styles'.
7. Such subject positions link knowledge and power. In other words, they enable and constrain understanding, experience, and action, thus maintaining particular social structures.
8. Discourses are able to take themselves as objects and reflect on the terminology they use.
9. Discourses are embedded in one another and are thus inter-referential, e.g. contradictions within discourses may reveal operations of resistance to other discourses.

10. Discourses have ideological effects, i.e. describing and reproducing particular, hierarchical power relationships, practices, and truths.

The above criteria will serve as a guide for the exploration of the discourses flowing through people with cancer's self-constructions, and the role of psychosocial oncology in the manufacture of such discourse.

The actual analytic process will involve a great deal of reading and re-reading. No attempt will be made to look for the 'gist' or main point intended by the speaker. On the contrary, the details of the passages of discourse will be examined; what is actually said or written, and what such statements imply. Firstly, pattern will be searched for in the data. This pattern takes the form both of variability; differences in either the form and content of accounts, and consistency; the identification of features shared by accounts (Potter & Wetherell, 1987). The same patterns, for example, could keep on occurring in the way the object and subject is constructed.

Secondly, the functions and consequences of apparent discourses will be explored. A basic theoretical thrust of discourse analysis is the argument that people's talk fulfils many functions and has varying effects (Parker, 1992; Potter & Wetherell, 1987). Hypotheses about these functions and effects, both at a micro-level (what is it doing for the speaker) and at the macro-level (what social structures is it maintaining or challenging), need to be postulated, and linguistic evidence will be searched for.

The main thrust of the second stage of the analysis will emerge through the exploration of rhetorical strategies. People's talk (rhetoric) draws on discourses in patterned ways, and aims to accomplish certain objectives; i.e. it acts strategically. It may be possible, for example, to note that two or more discourses are drawn upon by a sample of people. What may be of crucial significance, however, is the rhetorical domination of one of these discourse over another. In other words, people may use recurrent rhetorical strategies (Harris, Lea, & Foster, 1995) to maintain the dominance of one discourse over another (concerning a specific context). Through such an analysis of rhetorical strategies, more light will be shed on the broader dynamics between and across discourses, and what functions and implications they have for people. In other words, an understanding will aim to be gained which can explain why a particular discourse (or self) aims to dominate another discourse or self. It is necessary, therefore, to look at conflict; at instances where contrasting discourses clash; and how the conflict is resolved, or made sense of by people.

In the report emphasis will be placed on the interpretative process. Segments of the text, in this regard, are not examples which illustrate the data/results, they are examples of the actual data itself, they are what is under investigation.

9. CONCLUSION

Psychosocial services might have the potential to help people with cancer deal with their situation, but this has not translated into reasonable levels of utilisation. In order to understand this resistance, an approach has been argued for which brackets the 'truth' of psychosocial oncology and examines instead what sense the subject (the person with cancer) is making of psychosocial oncology and its services. In this chapter the person with cancer was presented as a novelist-historian who makes sense of his or her life and situation using various discursive resources which purport to have something to say about the 'reality' of this experience. By accessing various discursive models of 'reality' and the self, the person with cancer is able to construct, not only a reasonably coherent world and self, but multiple realities and selves, serving a variety of different functions. There are no naturally occurring 'psychosocial consequences' in this regard; only discursively constructed experiences. Since such experiences are at least partly constructed by discourses which have something to say about the cancer experience, the spotlight is thus obviously placed on psychosocial oncology and its associated services. Far from simply reflecting a given state of affairs, and providing a set of useful yet 'neutral' interventions, the system is, in fact, actively saying something about life with cancer and how to go about dealing with it. Such unavoidably *prescriptive* messages appear to be rejected by people with cancer. Why they are rejected will be investigated in the next chapter. This task shall be accomplished by asking people with cancer themselves why they avoid psychosocial services. An analysis of such conversations will aim to expose the rhetorical strategies used to nullify the messages from psychosocial oncology, *and* will attempt to understand why and how such rhetorical strategies are mobilised. The roots of the discontent will be searched for both within the messages of psychosocial care and the various selves of the person with cancer.

CHAPTER 5

RESISTANCE TOWARD PSYCHOSOCIAL CARE : A DISCOURSE ANALYSIS

1. INTRODUCTION

The previous chapters have set the stage for the final and most important part of the study; a dialogue with people with cancer. It has been argued that the person with cancer is not a 'natural object' existing out there in the world ready to be revealed to us by rigorous investigation. Neither is the person with cancer a unified self, open to illustration by unified theory. On the contrary, it has been argued from a discursive standpoint that the person with cancer, like us all, is in a continuous and multifaceted state of manufacture. Although we certainly are embedded in broader sociohistorical power structures and are thus *already* manufactured, the kaleidoscopic character of modernity combined with the disrupting impact of a cancer diagnosis enable a continuous process of re-designing the self. Psychosocial discourses in this regard thrust themselves on the person with cancer in various manners. The end result, however, is a rejection of various aspects of the system of psychosocial care, and a contrasting embracing of the concept of fellow patient support. To understand how and why this happens it is necessary to talk to people with cancer, and examine how the various psychosocial discourses fit in the multifaceted web of rhetoric we call the self.

2. METHODOLOGY

2.1. FOCUS GROUPS AND INTERVIEWS

The present qualitative approach demands dialogue with people with cancer. In line with the theoretical model outlined earlier, it is necessary to engage people with cancer in conversation and even argument, so that the process of discursive construction can be observed in action. This part of the study seeks to examine how people with cancer make sense of their lives, and their attitudes toward psychosocial care, as they speak and argue. It is in this sense that focus groups and individual interviews were selected as the data gathering techniques.

Focus groups are an increasingly popular means of gathering data, both in health education research and marketing research. This technique consists of small group discussions moderated by a group facilitator who 'focuses' discussion on certain pre-arranged issues. A great deal of leeway is nevertheless available to follow interesting avenues in the discussion. The focus group interview, in this regard, has several specific advantages (Basch, 1987; Stearman, 1994):

1. Respondents are all in 'the same boat' which enables more free-flowing and confident conversation. The intimidating effect of an 'interviewer' is off-set by the dominance of groups conversation and interchange (as opposed to a question-answer format).
2. Focus group interviews enable creative responses, since one person's commentary may 'spark off' ideas and feelings in other respondents. Focus group interviews frequently elicit far richer data than individual interviews.
3. Differences are highlighted. Respondents will obviously have differing ideas and opinions which soon take centre stage in the group discussion. This is particularly important for our purposes because the aim is to elicit argument and debate concerned with psychosocial care
4. The social and cultural influences are highlighted because the actual research process is very definitely a social encounter. No attempt is made to 'isolate' variables and subjects. On the contrary, social beings are observed in a social context.

Although focus groups are generally recommended to consist of 6-12 participants (Basch, 1987), mini-groups consisting of 4-5 respondents were selected as the method of choice since the present topic was rather sensitive. In this way a more intimate and secure climate could be created, enabling respondents to speak openly about relatively personal issues.

Several personal interviews were also conducted with some of the more psychologically distressed scoring respondents. Focus groups were deemed inappropriate for such people, since it could be possible that they would feel intimidated by the group context. Although interviews are useful means of eliciting in-depth data, it must be acknowledged that the presence of an interviewer (perhaps perceived to be a psychological professional of some sort) could influence the results quite significantly.

2.2. THE SAMPLE

Two focus groups were conducted with participants drawn from the survey sample. Most focus group research has tended to utilise relatively homogeneous samples so that relatively consistent data is elicited (Basch, 1987). Such an approach is based, however, on the assumption that people do have relatively consistent, non-contradictory, and stable 'attitudes' toward things. As discussed in the previous chapter, however, discourse analysis is interested in difference, contrast, and conflict. In such a situation participants are forced to mobilise rhetorical strategies which can construct and re-construct their position, continuously making sense of their scenario as they are faced with further conflict and contrast. As a result the focus group participants in this study were diverse across sex, 'race', cancer type, social status, and level of psychological distress as elicited by the Hospital Anxiety and Depression Scale.

The demographic characteristics of the focus group participants are shown in Tables 21 and 22.

Table 21: Focus group 1; demographic characteristics.

Respondents	1	2	3	4	5
Age	50	20	47	51	22
Sex	Male	Male	Female	Female	Female
'Race'	White	Coloured	Coloured	White	White
Language	English	E/A	English	English	English
Marital Status	Married	Married	Married	Married	Single
Earning status	2	1	1	4	4
CaType	Lymphoma	H&N	Breast	Breast	Lymphoma
CaStage	2	3	2	2	2
Treatment Stage	Remission	Remission	Remission	Remission	Remission

Table 22: Focus group 2; demographic characteristics.

Respondents	1	2	3	4
Age	56	55	51	56
Sex	Female	Female	Female	Male
'Race'	Coloured	White	White	White
Language	Afrikaans	English	English	English
Marital Status	Married	Divorced	Married	Married
Earning status	1	1	2	2
CaType	Breast	Breast	Breast	Lymphoma
CaStage	1	1	1	4
Treatment stage	Remission	Remission	Remission	Palliative

Four interviews were also conducted with various depressed scoring patients on the rating scales (HADS and BDI). The results of the survey indicated that people with cancer, in particular depressed people with cancer, had difficulty expressing their reasons for not seeking out psychosocial services. Due to the sensitive nature of the topic, it was thus decided that individual interviews would provide an effective means of eliciting data. The demographic characteristics of the respondents are shown in table 24.

Table 24: Interviews; demographic characteristics.

Respondents	1	2	3	4
Age	57	51	41	32
Sex	Female	Male	Female	Female
'Race'	White	Asian	Coloured	Coloured
Language	English	English	Afrikaans	Afrikaans
Marital Status	Married	Married	Married	Single
Earning status	2	2	1	1
CaType	Lymphoma	Lymphoma	Breast	Breast
CaStage	1	2	1	1
Treatment stage	Remission	Radical	Radical	Remission

2.3. PROCEDURE

While conducting the survey, the researcher explained to all relatively verbal (talkative) respondents that this study was being continued in the form of informal groups discussions and interviews. These respondents were asked whether they would like to participate. In such a manner a list of approximately 30 eligible participants was elicited. Eligible participants were contacted telephonically and given a choice of 6 focus group time slots. After a period of organising and re-organising time slots, two focus groups with respectively 5 and 4 participants were conducted. These focus groups were conducted at

William Slater Hospital in a comfortable group therapy room, with refreshments, and were moderated by this researcher (who has some experience moderating focus groups). The facilitator's discussion guide can be found in appendix D. The discussions were tape recorded and transcribed verbatim. The transcripts of the focus groups and the long interview can be found in appendix E.

Some of the depressed scoring participants consented to a tape-recorded personal interview. Three of such interviews were decidedly brief and took place at Groote Schuur Hospital in a consulting room. One long interview (2 hours) was conducted at William Slater Hospital.

2.4. ANALYSIS OF RESULTS

The discourse analysis was guided by Parker's (1992) earlier outlined suggestions regarding the procedure of discourse analysis, and Harris, Lea and Foster's (1995) example was loosely followed regarding the reporting format. In the first section, two broad discourses are identified and described, as separate 'objects' of study (i.e. taken beyond the talk of the respondents). Some liberties were thus taken to present a picture of the type of world these discourses demarcate. This is not to say that a person would actually find him or herself totally eclipsed in such a world. Rather, the inherent dilemmas within discourse (Billig et al., 1988) frequently necessitate an avoiding or a reformulating of certain 'unsavoury' implications of an argument. In the second section, a detailed examination of the various rhetorical strategies used by respondents is presented. Such rhetorical strategies use the resources of the outlined discourses to define the rules of its argument, and it is at this level that the dominance of one discourse over the other actually presents itself.

3. RESULTS: TWO DISCOURSES

3.1. INDIVIDUALISM: THE RATIONAL ‘I’

> *“I just felt I had cancer, I was having treatment, I didn’t feel well. I didn’t feel like going along to a meeting hearing about other people’s ailments. It was too much.”* (I1)

> *“each one lives with his own fear” (survey)*

One particular discourse dominated respondents’ accounts of their lives and experiences as pertaining to their illness. Within this discourse the subject is constructed as a fundamentally rational and free agent who is capable of making choices in the face of adversity. At root of this discourse lies the “I”; not an abstract or theoretical concept (such as the psychological “self”), but the “I” that lies at the very root of one’s existence and identity, the very enabler of personhood. One could regard it as the “I” in the statement “I have a self”.

The “I” is thus fundamentally separate from anything else in the world, with the result that the cancer is seen as an extraneous threat one must “handle” or “cope with.” The “I” must face cancer as a life crisis and attempt to overcome it. As the following quotations exemplify, such a battle depends on one’s “attitude” towards the crisis and oneself.

> *“I have to get up, be my own boss and get my mind right.” (F2)*

In this case the respondent is putting particular emphasis on the control he has over his life. He as agent decides how he will be when he wakes up in the morning. He has authority over himself and as a result is capable of getting his “mind right.” The “power of the mind” was, in this regard, often called upon to maintain a “right attitude”, as the following quotes exemplify:

> *"I believe very strongly in the power of the mind. For some people it is religion. For people who don't have religion the power of the mind can do fantastic things to your body." (F1)*

> *"Motivation has always played a big part in my life. It is the mind that motivated bad attitudes to get back to right attitudes." (F1)*

The above quotation eloquently describes the image of a rational and free agent residing somewhere in the mind, controlling the mechanics and variables (attitudes) in that very mind. The "I" thus occupies prime position in the hierarchy of agency; it even sits behind 'mind' and 'attitudes'.

At base only the "I" can deal with cancer because only the "I" has cancer. It is only the rational agent residing in the mind who ultimately is required to accept the cancer and develop the "right attitude" towards it. As a result the experience is at heart a lonely one.

> *"I have had contact with a social worker and she had cancer before. The important thing that she said to me was having been through it you have to build yourself up. You have to come to terms with yourself. Whatever anybody says from outside what actually happens in here and the thoughts you have yourself are what ultimately makes you cope with it. Having been through it and come to terms with it and said 'I am going to get on with my life. I am better now. I am going to make the best of what I have got left' makes you a stronger person. She said to me 'it is horrible to think that we have got to go through this terrible illness or some terrible experience to come out the other side a stronger person.' But having been through something like that you do come out a stronger person. You have much more sympathy and understanding for people." (F2)*

Ultimately therefore, one is caught in a subjectivity from which one cannot escape (*"what actually happens in here"* is all that counts). It is just "me" and the cancer thing, and the only thing one can do is come to terms with it. No one else can comment meaningfully on it because they are not "practically" in the "inside".

> *"If I got a call at home asking if I was interested to come to a support group. Maybe I needed that push. But for me, one person ill, you feel you have got to handle it alone."* (I1)

The above discussions and quotations have, quite basically, described the essence of Western individualism. Within this world we exist as rational and encapsulated "I"s gazing upon a distinct and separate world. This scenario appears to be rooted in Descartes' mind-body distinction (the encapsulated cogito) and various religions' emphasis on the rational and free 'soul.' Not only the world is separate in this regard, but even our bodies and our emotions are separate 'objects' we could potentially control. Emotions may certainly be provoked but we are blessed with the power, *and duty*, to control and regulate our perhaps rather spontaneous and primitive emotional impulses. Individualism, by its very name, refers perhaps most importantly to the idea that we exist as separate individuals; we exist as encapsulated "I's" totally separate from the world and other "I's." Academically this leaves us with the thorny problems of subjectivity, but at an experiential level this results in a fundamental loneliness. The person with cancer is fundamentally alone in his or her situation. Only the victim can know what it is like to be that victim, and as a result it is at base only the victim who is required to do the "coping".

Although the above describes what appeared to be the essence of the individualist discourse, some related themes consistently accompanied and qualified the individualist assertions. Support from others, for example, was regarded by most as vitally important, but only from four sources - family, friends, faith/religion, and the doctor. Such relationships were constructed as "natural", in the sense that they are normal and rational in a physical, biological, religious, and social sense. One's family and friends are natural sources of love and caring, one's God and faith comfort the lonely soul, and one's doctor is the vital bridge towards cure.

> *"My faith was the most important and my family. My doctor was very good to me." (F1)*

> *"I got plenty of support. We are a very close knit family." (I2)*

> *"If you have got something that bothers you can go to your priest."*
> *M: "Does that help for you?"*
> *"Yes. He is always there to say something that makes me feel better." (F2)*

For some, speaking to fellow patients provided comfort. Such encounters "normalise" and legitimise one's feelings. One realises that one's feelings are normal reactions, and that one certainly is not the only one facing this dreaded disease. Such "comradeship" thus appears to ease to some extent the fundamental loneliness of the cancer experience.

> *"One thing I did find was during treatment and just after, one of my symptoms was a very dry mouth and it woke me up at night. You don't appreciate the saliva in your mouth until you haven't got it. Just going for a check up one day there was a young chap who used to go for radiation at the same time as me and I hadn't seen him since we had both finished our treatment. Seeing him there was like seeing an old long lost friend. I asked him how he was and he said he had a terribly dry mouth that was driving him mad. I told I was pleased and he asked what I meant by that. I told him I had that too. I hate talking ailments to friends, I find it terribly boring but sometimes when people have gone through the same thing and they say 'I found such and such' or 'emotionally I feel this', you realise you are not alone." (I1)*

Relationships with other people are thus based on mutual respect and a "natural" sense of "relating." Rational and responsible agents "relate" in an authentic manner, and the closer the relationship is in terms of time, familial links, or experience, the more authentic or "real" it is.

The probable religious roots of the individualist discourse were highlighted by the frequent referrals to a "faith" in God, and its beneficial effects. The broader cosmic meaning of the world and one's place in it were obviously of vital importance, particularly as the context within which one makes sense of one's life with cancer. For one, such beliefs can ease the fear of death.

> *"I can't remember being shocked when they told me I had cancer...I don't have any fear of dying because I believe there is a better life hereafter." (F2)*

Cancer is sent either by God or fate as a moral challenge. As a result faith is particularly important in dealing with this challenge. Believing that the event has some higher purpose, or that it was sent to test one, can strengthen one's morale in the battle. It does not necessarily have to mean anything cosmic, but it must be regarded as a moral test of character - an occasion whereby the "I" can affirm his or her "dignity", "courage", and moral "strength". Even suffering itself can be imbued with moral-religious meaning. In many cases it is something that has to be experienced, something that people throughout the ages have experienced, and something that one's God (e.g. Christ) has had to experience. Ultimately suffering is an essential aspect of the concreteness of life-meaning, and as a result has to be experienced, and more importantly so, has to be experienced by "myself".

> *"When you are a patient you are challenged. Religion is valuable. I am challenged by the Bible. I was the youngest patient in the ward and the doctors didn't want to tell me I was very ill. The doctor told me she didn't know how I survived. What happened to me spiritually in the hospital is beyond what words can describe." (F1)*

Such power is not a universal given, however, and thus needs to be nurtured through "faith" in oneself or in one's God. Either way, one must first believe that one can control one's attitudes and one's destiny. Note in this regard the continuous emphasis on *belief*, as opposed to feelings and emotions. One's thoughts, attitudes, and faith are potentially under the control of the free will, and determine one's general state of being.

> *"Whether the faith we have comes from your religion or whether it comes from within helps. Building up faith and confidence in yourself is important." (F1)*

Accepting one's lot in life also lies at the heart of successful coping. It is only when one accepts the crisis and suffering that one is able to move forward and be whatever "one is".

> *"Once you have accepted it you make the best of it. Be whatever you are." (F1)*

Acceptance leads to a rational and practical assessment of the situation (in turn leading to a "make the best of it approach"), and thus in a sense a realistic or natural state of affairs ("be whatever you are").

Although the individualist discourse is certainly a rather 'tough' world to live in (in terms of the pressure exerted on the "I" to live up to the challenge with courage and strength), it does ultimately offer significant growth, dignity, and positive meaning in suffering.

> *"But having been through something like that you do come out a stronger person. You have much more sympathy and understanding for people." (F1)*

These positive aspects cannot be underestimated. The individualist discourse is not a simple storyline framing the cancer experience, but is an entire worldview which imbues life with meaning and purpose. For centuries it has offered a way of making sense of the chaos and untold suffering in this world. In the context of cancer, therefore, it quite evidently is not only a powerful discourse, but in a many cases an essential one.

3.2. THE PSYCHOLOGICAL DISCOURSE: THE EMOTIONAL 'MIND'

> *"I did have my support group and wailing wall where I could be myself... The cancer wasn't the issue. It was expressing the depression, the stress, the pain, the uncertainty, the fear, and the anger. I wasn't judged. I didn't have to be anything that I wasn't."* (F2)

A minority of respondents occasionally utilised what could roughly be called a psychological discourse. Here a diagnosis of cancer presents a situation of emotional crisis which needs to be carefully dealt with. As the quotation below illustrates, the "I" is not as central, and neither is the battle between the cancer and the "I". On the contrary, the object in this discourse is more the emotionally charged - and chaotic - mind, which needs to be (objectively/abstractly) "clarified", "expressed", and "guided" toward integration and resolvement. Such "growth" is not enabled by a tough and resistant attitude towards the crisis, but by emotionally easing balance and harmony ("don't kick against it".)

> *"What I found the most therapeutic was going to a friend who had the same as I and we just cried. Those first four days I was numb. I really walked around like a zombie. Then came the acceptance of it. What helped me through was that I didn't kick against it. Not that I was like a dead fish going downstream and saying 'do what you like with me.' I went along with it." (F2)*

In the above quotation the respondent describes her moment of shared grief as "therapeutic"; or in other words, a moment of social interaction is constructed as a healing encounter (as opposed to a "normal" or "destructive" encounter). The mark of such a therapeutic encounter is the expression of emotions. It is such expression which in a sense relieves one of the suppressing emotional energy and at the same time puts it on the table ready for "clarification".

> *"It is possible to maybe have some of my own emotions explained. One does get very mixed up and not knowing how you feel." (I1)*

The centrality of emotions are emphasised here, and contrary to the individualist discourse, play a primal role in determining the nature of the self (more so than the "I" - "not knowing how you feel"). In other words, the emotions can have a life of their own, and as a result need occasional "clarification" so that personal control can be regained over them.

The present discourse was termed psychological because it quite evidently is a conglomeration of psychological principles. It is here that we see the infusion of psychological theory in popular culture; the accessing of psychological "facts" in order to make sense of one's world and situation. Although respondents may have been accessing various psychological theories, on the whole the basic principles of psychodynamic theory dominated. Several authors have commented on the wide spread popularisation of this theory, identifying it as an increasingly important aspect of Western culture (see Parker, 1992). The occasional reference here to the supposed emotional complexities of the mind testifies to such commentaries.

Most importantly, however, the psychological discourse carries significant implications to the nature of social interaction, and perhaps more importantly, to the *therapeutic* capacity of social interaction. As alluded to above, human interaction is decidedly more complex within this discourse; a complexity best explained by drawing on psychodynamic theory. Far from being plainly rational, relationships can, according to psychodynamic theory, be influenced by various unconscious motives, and in some cases steer them unwittingly into destructive directions. In most cases, people are unaware of the psychic purposes certain 'neurotic' relationships might serve. As such, if 'therapeutic benefit' is to be derived from a certain relationship (e.g. counselling or group discussion) then it is recommended that a trained facilitator or therapist moderate the encounter. Such a conceptualisation does, however, rest on the assumption that psychological perspectives are somehow scientific, neutral, or non-judgmental. It is this characteristic which gives the professional relationship its distinctive edge. The respondent below, for example, utilised support sources at her place of work (a counselling centre). Although she could have accounted for her behaviour by explaining that she received support from her work friends she opted for the psychological discourse and thus constructed the relationships as "non-judgmental" therapeutic environments.

> *"I gravitated to the counselling service where I was familiar and where I knew I was going to be accepted for who I was and where I was. Nobody was going to say 'I had to be this or that' and people would have time for me. ...would end up at the counselling service because I happened to know them there. If I wanted to talk to somebody I could. If I wanted to do something I could. It was just a space where I could be me."*
> *"Do you feel that you wouldn't be allowed to be you in a psychiatrist's office?"*
> *"I gravitated where I knew I could be. I didn't go to my sister because she would cry with me. I didn't go to the minister because he would have to play a role." (I1)*

The centrality of the emotions as an independently operating dimension of one's mind (and the concurrent need for a body of expertise and experts) ultimately destroys the essence of the rational "I". Most respondents, in this regard, explained that professional help would only be required when one looses total control.

> *"2 years after my mother's death my boys went to the army one after the other and my husband lost his job after 25 years. That was 3 major losses in 3 weeks. I didn't cope with it, I went on and on. Two years later I hit the deck and I couldn't cope. I was deeply depressed and not understanding what was there. I went to my GP who referred me to a professional guy. I did need professional help then."*
> *"Did he help you?"*
> *"Yes. I didn't go for many sessions. The fact that I understood that it was a reaction that I hadn't worked through, I had pushed aside, was a relief. I realised that this was the process that had happened." (I1)*

As is apparent, this respondent (the same full-time counsellor respondent as above) made extensive use of the psychological discourse to explain and justify her use of professional care. Precipitating the problem were three major "loses" (a basic psychodynamic principle) which resulted in a state of "not understanding what was there" (loss of agency). Professional help was obtained through medical channels (making it a legitimate medical problem), which in turn helped her gain "understanding" that it was a reaction she "hadn't worked through." The problem was, in other words, very classically an issue she had "pushed aside", i.e. repressed.

Other respondents described similar scenarios, but avoided positioning themselves in this discourse.

> *"There is a need for psychiatrists. If your mental state is in a situation where you can't solve it yourself and you are mentally screwed up the only course open is a psychologist/psychiatrist." (F2)*

In the above case, the respondent illustrates a situation of total loss of agency, i.e. the person is "mentally screwed up" and can't solve the problem him or herself. The psychological discourse is mobilised, in other words, only when the rational "I" has been utterly destroyed. In such extreme circumstances there obviously is no alternative to professional intervention since one's very identity as a rational being has ceased existing. Such extreme cases were most often conceptualised as internal 'defects'; in other words, the person is a priori "mentally screwed up." Note below how the respondent identifies her cousin as a "neurotic" person - the person's very identity is "neurotic."

> *"Different people have different stages, different depths. I have a cousin who if she had been in my position she would have definitely needed a psychiatrist."*
> *M: "Not a counsellor?"*
> *"Probably not. She would have needed a psychiatrist. She is totally neurotic. Maybe she would have gone via a counsellor but in the end she would have needed a psychiatrist." (I1)*

A definite hierarchy of well-ness is thus implicit in this discourse, ranging from a still rational "I" having to deal with moments of "emotional unclarity" to the utterly destroyed

"I" who needs immediate psychiatric intervention. The further one slips down the hierarchy the further the destruction of the "I".

3.3. COMPETING IMAGES: MENTAL HEALTH VERSUS MORAL VICTORY?

As we have seen, the prototypical images of good copers and bad copers expressed by each of the above two discourses, and the processes determining the production of both, oppose each other quite radically. This is not to say that respondents were either solely individualistic or solely psychological. On the contrary, respondents tended to slide from one to the other, using them as rhetorical devices to make sense of different things at different times. It must be emphasised that reference is being made here to discourses as abstract objects of study (Parker, 1992), and it as abstract objects that they radically oppose each other. The individualist discourse assumes rational (cognitive) control over emotional well-being, whereas the psychological discourse puts more emphasis on the notion of psychic forces (emotional dynamics) operating independently and out of direct control of the rational "I". Thus when the psychological discourse frowns upon "facades" or "illusions" of coping, arguing that one should not attempt to be "tough" or "strong" since that will only "suppress" the chaotic emotions, it is in another sense attacking the self-perceived rationality of the "I" and its sense of personal control over mind and body. This idea of a separate psychic "organ" (over which "experts" are able to give meaningful commentary) is not just a threat to the *extent* of the "I"'s personal power over self, but is an assault on its very identity as a rational and cognitive agent. By expressing one's emotions and seeking professional help one is in a sense abandoning the "I" and "giving in" to the psychic organ.

At the extreme end, the psychological patient thus exemplifies the failed individualist. Here is a person who is unable to handle his situation, who has compromised his or her "I" in the pursuit of some vague notion of "psychological integration" or "mental health." This person uses "artificial" support (counsellor, therapist, support group), has lost her dignity, and most importantly has lost her rational “I”. Instead of understanding cancer as a moral and religious challenge, something which needs to be faced with strength, resolve, faith, and quite acceptance, the psychological patient is after hedonistic “mental health”, some form of superficial “happiness” that is completely out of tune with the broader meaning of life (and the after-life).

The above discussions have set the conceptual stage. Two broad discourses have been identified, which at a conceptual level conflict rather dramatically. In actual conversation and dialogue, however, respondents sometimes accessed both discourses serving different functions at different times. An examination of the rhetoric used by people will aim to illuminate what such functions may be.

4. RESULTS: RHETORICAL STRATEGIES

Although some respondents used both the individualistic and psychological discourse to make sense of their experiences, it was nevertheless clear that the individualistic discourse was at all times dominant. Most respondents would only utilise the individualistic discourse and thus dismissed psychosocial care in an uncomplicated manner. Others however, particularly the depressed scoring respondents who were interviewed individually, had a more difficult task constantly needing to make sense of the inherent contradictions between the individualistic and psychodynamic discourses. But even in such situations, respondents were adept at using various rhetorical strategies so that dominance of the rational “I” was retained. By actively reconstructing diverse and dilemmatic accounts using the various meanings and positions in the individualistic discourse (Harris, Lea, & Foster, 1995), such rhetorical strategies managed ultimately to produce and reproduce a meaningful rational “I”.

Meaning in suffering: the coping "I"

On asked why they were not interested in using psychosocial care, the majority of respondents answered simply that they did not need it - they were "coping" as is.

> *"I have been married twice and now I am on my own. I am coping extremely well. I don't get depressed...I am on my own." (F2)*

The primary characteristic of the above type of response is the emphasis on the "I" who is doing the actual coping, i.e. the utilisation of the individualistic discourse. The above respondent highlighted this theme with exceptional vigour by emphasising how she really did accomplish it all on her own.

Within the individualistic discourse the "good coper" has chosen to respond to the cancer with a spirited and positive attitude, and as a result can pride him or herself on this accomplishment. Coping with cancer is thus the ultimate affirmation of moral personhood - one has managed to stand up courageously to death. By employing the individualistic discourse one is not simply utilising an arbitrary discourse, but one is actively claiming a moral victory. One need only read Victor Frankl's (1959) account of his concentration camp experiences to understand the force of such victories, and realise why it affords him the theoretical claim that meaning can be found in suffering.

Such inspirational storylines are not "mere" storylines, and neither are they simply "macho" attitudes standing in the way of therapeutic expression of emotion. The moral victory is caught up in the individualistic discourse, and as it now stands, the individualistic discourse forms the basic structure of our broader Western world view (and the various institutions that come with it - e.g. the legal system). It can be assumed, that for most people in the West, the individualistic discourse is the storyline which makes life, and certainly life with cancer, at all liveable.

Nevertheless, dilemmas are prevelant not only accross, but also within discourses, and as such need to be made sense of through argumentation and rhetoric (Billig et al., 1988). A problem occurs, for example, when one attempts to conceptualise the moral "bad coper" in the light of our current "humane" social ethic.

Bannishment to madness: The poor coper and the loss of "I"

As mentioned, both the individualistic and psychological discourses embody hierarchies of wellness. Although both images of the "good coper" were relatively clear, the moral "bad coper" seemed difficult to conceptualise. Using its internal logic, this unfortunate would be characterised by his or her lack of moral "strength" - his or her inability to face up to the crisis with courage and fighting spirit. Since such an attitude is ultimately a moral and rational choice, however, one is forced into a position whereby the "bad coper" is blamed for his or her poor performance. The "bad coper", in other words, deserves his or her poor lot in life. Such a medieval conclusion is clearly unreasonable in a society which considers itself "humane." Several authors (Foucault, 1977; Riesman, 1983), for example, have commented on the historical shift in the approach to the disciplining of behaviour (curtailing deviance), from overt punishment to "humane" caring. This movement towards a "medicalisation of life" moves the "problem" away from the rational and free "I" towards the domain of biological "nature".

Many respondents, in this regard, described the poor coper as a person of "weak character" who simply "can't take it."

> *"..Some people might need counselling because they can't take it." (I2)*

> *"A lot of people take this up differently. Someone will hear that they have got cancer and they will go see a psychiatrist. It depends on how strong you are as a person if you will need a psychiatrist." (F1)*

The poor coper, therefore, has something fundamentally wrong with him or herself as a person. He or she is somehow of "weak character". In accordance with such medicalisation, the weakness of character is invariably linked to some form of psychopathology. The respondents below, for example, equates being weak as a person with being "neurotic".

> *"I am not neurotic. I have got quite a strong mind. I am not a weak person. You do get people who if they had cancer it would play on their minds terribly. They would become very depressed." (I1)*

> *"I do not feel that I needed any of the services available. The melanoma has not changed me nor my outlook in life in general." (Survey)*

In the above quote the respondent emphasises that neither she as rational "I", nor her "outlook on life" have changed as a result of the illness. The language carries with it the implication, therefore, that the illness could possibly alter one's very identity ("me") and one's "outlook on life". Such a person, according to the internal logic of the individualistic discourse, would be utterly destroyed since he or she has lost the very essence of being a person - knowing and controlling who one is, and the "outlook" one chooses to have of life.

On asked to describe the type of people who use psychosocial services, most respondents described people "who can't cope", people who are "depressed", "suicidal", or "mentally screwed up". People who use psychosocial services have thus lost the moral battle because they are "weak" or "sick". By losing the battle the individualistic and rational "I" is destroyed - they have something wrong with their "mind" or they are ill as "people" (their entire identity as people - personhood - has changed) - in other words; not guilty by way of insanity.

This rhetorical strategy makes the prospect of some type of harmony between the individualistic and psychological discourse problematic. Due to humanist pressure on the individualistic discourse, it has become necessary to avoid the unpleasant ruthlessness of blaming people for their misery. As a result, aspects of the psychological discourse are used to in effect destroy the rational "I", thus absolving it of guilt. What was a hierarchy of wellness is now a categorical division; a chasm between the individualistic "I" and the pathological "mind". This poses the question of how respondents make sense of their own distress; if they have rational control over their feelings how could they possibly have any feelings of distress?

Battle wounds: reactions and adjustments

> *"What type of people go to a psychiatrist?"*
> *"People who can't cope or can't find peace of mind. Last month I felt down in the dumps but I think it was an adjustment of not being in that routine anymore, i.e. being at work from 8 a.m. to 5 p.m. I worked for 35 years. I have to get up, be my own boss and get my mind right. I find myself reading a paper sometimes staring. That is not from the cancer but it is just a readjustment. I can't sit still and do nothing." (F2)*

After describing the deficient poor coper, this respondent goes to pains explaining that he does not fit the picture he has just painted of such a patient. His distress is simply a "readjustment" and has nothing to do with not being able to cope. It is a temporary reaction that has nothing to do with a deficiency in him as a possible poor coper. He also justifies himself by highlighting the extent of the change in lifestyle. By appealing to his work ethic and his ability to "get his mind right" this respondent is continuously reaffirming the individualistic discourse and his successful position in it.

> *"I didn't go totally neurotic. I am not a neurotic person but I had my quite moments." (I1)*

The above quotation effectively illustrates the resistance to a pathologised positioning. After explaining some of her distressing feelings she qualified her explanation by emphasising that she did not become "neurotic", in other words, she did not become pathological. Instead she experienced what she calls "my quite moments", *my* temporary and private moments of grief. Although not going as far as claiming agency, she is claiming ownership of her feelings - those are *her* moments of grief not open to further external interpretation.

According to Parker (1992) a discourse can refer to itself and to other discourses. Billig et al. (1990) put emphasis on a similar notion by illustrating the dilemmatic nature of "ideologies" (or discourses). According to these authors people need to continuously argue and debate (either externally or internally) the various dilemmas across and within discourses, always attempting to reconstruct their lives using the various discourses. Such debate is effectively illustrated by the quotation below:

> *"I have lots of support from friends and the church who have prayed for me and with me. That is why I have never been to a discussion group like this because I never had the need for it. I am no hero. I have also spent weekends crying when I was down in the dumps. That was because of my last chemo." (F2)*

Initially this respondent locates himself firmly in the individualistic discourse by describing the support he received from his friends and church community (a "natural" source of support). Perhaps feeling rather out of place in what in many ways feels like a support group (the focus group), this respondent does qualify his positioning by toning it down. By using the statement "I am no hero" it can be assumed that this respondent is referring to the popularised critique against the individualistic discourse that it is "macho". He thus explains that he also expressed a great deal of emotions (and thus is also in some sense positioned as a psychological subject), but ultimately turns back to the individualistic discourse by attributing this distress to his "last chemo." In other words, although he acknowledges his emotional side and the need to express this aspect of the self, he nevertheless constructs such experiences as temporary reactions to physical pain. It is simply an understandable reaction and as such would not need "therapeutic" expression or clarification, or in other words, it is not something that threatens the rational "I." Thus although this respondent at a superficial level appears to be sympathetic to the psychological discourse, at a deeper level he has only reconstructed the individualistic discourse so as to neutralise the psychological critique.

The above case illustrates the way in which the individualistic discourse is able to claim dominance over the psychological discourse by using certain subtle rhetorical strategies. The extent of this subtlety, however, can sometimes take proportions whereby the very presence of the individualistic discourse is concealed from sight. Note the earlier referred to quote below:

> *"2 years after my mother's death my boys went to the army one after the other and my husband lost his job after 25 years. That was 3 major losses in 3 weeks. I didn't cope with it, I went on and on. Two years later I hit the deck and I couldn't cope. I was deeply depressed and not understanding what was there. I went to my GP who referred me to a professional guy. I did need professional help then."*
>
> *"Did he help you?"*
>
> *"Yes. I didn't go for many sessions. The fact that I understood that it was a reaction that I hadn't worked through, I had pushed aside, was a relief. I realised that this was the process that had happened." (F2)*

Although this respondent made comprehensive and sophisticated use of the psychological discourse to account for her own emotional life, it is nevertheless clear how she attempted to minimise this positioning. Only a few sessions were needed since all she needed was "awareness" to reclaim the primacy of the "I". The role of the psychosocial professional is thus minimised and instead emphasis is put on the rational "I"'s role in "understanding" and "realising" the process, and thus ultimately reclaiming control.

Such minimisation of the psychological professional's role was also effectively illustrated by the following piece of conversation:

> *"From a woman's point of view when they go out and seek help they don't want someone to come along and say 'do this, do that.' A lot of women say 'I can feel what you feel. I can sympathise with the problems you are having to deal with' and talk in a manner to bring that person's own thoughts out. You have to say 'these are the options.' The person has to come to terms with it themselves. Psychiatrists have to get the person who is affected to come to the decision themselves instead of 'do this, do that.'*
> *M: "So you feel that ultimately coping with something like cancer depends on yourself?"*
> *"You can be guided. You have got to come to terms with it. I don't know if a psychiatrist would say 'do this, do that.' Psychiatrists try lead the person to find the answers themselves." (F1)*

The above is an example of a commonly used attempt at incorporating the power of the rational "I" into a psychological positioning. Both the benefits of emotional expression in a therapeutic environment, and the necessity of "coming to terms with it themselves" are emphasised. The inherent contradiction between the two accounts are difficult to reconcile, however, and a détente is thus ultimately accomplished using the elusive statement; "psychiatrists try lead the person to find the answers themselves." Here again, a picture of a somehow passive professional (so that the rational "I" can survive) is painted, who nevertheless has to "lead" the person to the answers - an unavoidable contradiction.

"I have all the support I need" - from *natural* sources.

On asked why they are not interested in psychosocial care services, many respondents argued that they have all the support they need.

> *M: "How did you deal with it? Did you go to the Cancer association.?"*
> *"The Reach for Recovery people came round. My family was most important." (F1) -*

> *M: "What about support groups?"*
>
> *"I feel I don't need it. I have got family support which is more important." - (I2)*

Responses such as the above illustrate the way in which psychosocial services were sometimes understood by respondents. An assumption was frequently made that psychosocial care is a form of *social support* (as opposed to a form of psychological *treatment*). Although the term "support group" does lend itself to such an interpretation, it was nevertheless interesting to note that respondents generalised the social support assumption to other types of intervention (counselling, patient visits). This tendency can be interpreted in light of the individualistic discourse whereby supportive relationships are constructed as somehow "natural" (i.e. being a relationship of caring between family or friends). "Therapeutic" or "facilitated" relationships are difficult to make sense of using this framework, and are thus perceived to be "artificial" forms of social support which are inevitably poor alternatives to the "real" thing. The above quotes effectively illustrate the operation of this individualistic discourse, in the way it constructs psychosocial care as a lesser form of social support not comparable to the intrinsic value inherent in family relationships. Note below how the psychosocial care relationship is constructed as inferior to a "real" relationships since it is ultimately like talking to a "stranger".

> *"One doesn't like to burden strangers with your own personal thing. I wouldn't like to lay my trip on anybody else if I was depressed. I don't want to rely on a stranger for support. It is not fair on the stranger....I don't think I would go to a support group and collapse. In front of people you have be strong and tough. In a group like this I wouldn't burst into tears. Would you?" (F2)*

Psychosocial care givers are "strangers" and as such cannot be used for support. The individualistic discourse constructs the support group or counselling situation as somehow perverse, an undignified "collapse" in front of people who have no intrinsic obligation to be "burdened" by such an emotional outpouring. As illustrated earlier, the individualistic discourse is capable of referring to itself from an abstracted position, so that it may reconstruct itself in the face of mounting pressure from opposing frameworks. In the above case, the respondent acknowledges that "in front of people you have to be strong and tough", in other words, acknowledging that one may *actually* feel very different to the *facade* one is presenting to the world (thus slotting into the psychological discourse). Nevertheless, the argument ultimately is still framed within the structures of the individualistic discourse, since the expression to "strangers" of how one may actually feel is somehow still not "fair" (to the stranger) or "natural" (she is not "capable" of doing such a thing). The argument is implicitly carried forward to the conclusion that such an expression of emotion is justifiable only in the context of more "natural" (family, close friends, priest) relationships.

> *"If you have got something that bothers you can go to your priest."*
> *M: "Does that help for you?"*
> *"Yes. He is always there to say something that makes me feel better." (F2)*

As explained earlier, the criteria framing what may be regarded as a normal or real relationship within the bounds of the individualistic discourse also encompass what may loosely be called the "ability to relate to the person". This relatedness, as illustrated above, is implicit in relationships with family, close friends, and in some cases one's priest and/or doctor. In other words, the potential that family members will "relate" to each other is very high. The extent of this potential in other relationships was also extensively discussed, (and thus constructed), as pertaining to issues of class, cultural background, and personal experience (see the section below on fellow patients).

> *"It has to do with one's environment. You don't play with friends whose father is a doctor or psychologist...If a labourer was sitting in the chair I would feel happier. It is a different feel of a person to get used to." (F1)*

The above respondent from an underprivileged background explains, therefore, that he would have difficulty relating to a psychologist since he or she would be so far removed from his "environment" (which in turn has an unavoidable influence on the "feel of a person"). Far from being a neutral, non-judgmental professional or scientist, the psychosocial professional is in contrast constructed as a person from a distinct social class with a particular personal identity rooted in such an "environment." The psychosocial professional is simply another person who happens to be too far removed socio-economically and as a result would be exceptionally difficult to "relate" to in any "real" manner.

The above quotations and discussions have illustrated how the individualistic discourse constructs relationships between people as somehow needing to be "real" or "natural". The question therefore remains: what of the people who do end up using psychosocial care? How do respondents make sense of such behaviour in a humane manner (i.e. without dismissing it as simply perverse)? When asked to describe the types of people who do attend support groups or other forms of psychosocial care, responses such as below were typical.

> *M: "Who do you think goes to support groups?"*
> *"Someone who is feeling lonely, somebody not coping well or they haven't got family support." - (12)*

In light of the individualistic discourse, the user of psychosocial care is therefore again constructed as somebody "abnormal". This unfortunate lacks normal family relationships, is lonely, and is not coping well - a pretty dismal situation to be in and a true victim in all its senses of the word. Here we find the individualistic loser, the destroyed "I", who is victimised and medicalised and thus needs to be cared for.

Psychodynamic discourse as "culture": those silly Americans

The individualistic discourse was clearly dominant in most of the interview material, and although the psychological discourse was frequently referred to (since it was the very topic under discussion), it was more often than not re-constructed so that the individualistic discourse would remain unthreatened. As illustrated above, various strategies were used to construct the therapeutic relationship as somehow "unnatural", as a perversion or poor alternative to "real" relationships between people who can "relate" to one another (family, friends, people from same background). The expression of emotion to "strangers", according to this understanding, thus takes a somewhat "unnatural" or socially "abnormal" flavour - it is simply not done. Nevertheless, there certainly was recognition that a psychologized way of life was "done", and that it was growing in popularity. To make sense of such "unnatural" behaviour, many respondents took a different approach by reconstructing the psychological discourse as a "cultural" trend, or more specifically, as an American cultural trend.

All Americans, in this regard, see a psychiatrist (which obviously is ridiculous).

> *"From American movies you hear every second person saying 'I spent 2 hours with my psychiatrist'. It is getting bad vibes from the media because they are making fun of it." - (F1)*

Americans are culturally more emotionally expressive, and thus need psychiatric care.

> *"Maybe culturally we are different to the Americans. If you watch 911's emotional side it is quite foreign with men telling a story that happened 4 years ago and tears are running down their faces. I get the feeling they need psychiatric guidance." - (F1)*

And Americans are culturally quite paranoid or psychopathological.

> *"The Americans asked to be allowed to carry a Cyanide pill with them because of this fear they have had for many years that they are going to be attacked by the Communists and they want to be able to commit suicide quickly. The South African children/students don't think like that. American students feared that they were going to be wiped out and they wanted a quick death. We are not like that. We don't have this fear that the communists are going to take us over."- (F1)*

Underlying this strategy once again lie the structures of the individualistic discourse. Two points are worth discussing here. In the first place, emotional expressiveness is constructed as a cultural trend. The emotions, far from being regulated by the universal laws of the pancreatic psyche, are moulded by "culture". The emotions, in other words, are exceptionally fickle (without real substance) and are thus certainly an easy match for the rational "I". The Americans, by being culturally more emotionally expressive and paranoid, have rather absurdly let their rational "I" slip, and are thus in need of psychosocial care. The second point here, therefore, is that if one is "silly", "emotional", and "paranoid" (which, one must remember, are just cultural aberrations) then one needs psychosocial guidance. Psychosocial care, far from being a neutral, scientifically (medically) based enterprise, is constructed as a "cultural" fad for "culturally" obscure people.

This rhetorical strategy effectively illustrates how people are able to draw on various sub-discourses (and thus use varied rhetorical strategies) in a varied and flexible manner (Parker, 1990). In some cases the user of psychosocial care is constructed as a pathological victim, and in other cases as a culturally deviant fool. In the first instance a somewhat essentials account is used and in the second a normative (or cultural) account is used. Either way, however, the authenticity and "realness" of the individualistic discourse is protected.

De-professionalization: don't mess with *my* grief

The latter half of this century has witnessed a mounting intellectual (and sometimes violent) assault on authoritarian social institutions. The Government official, the priest, the army officer, the schoolmaster, the parent, the academic, and even the doctor have experienced significant changes in the way they feel they *should* do their business. Not that this process has in any way ceased, as any professional battling his or her way through conservative and progressive elements will testify. More seriously than ever before, people who find themselves in positions of power are asked to justify and legitimise the power they wield. Although respondents expressed an enormous amount of gratitude and respect towards their treating doctors, for many this was certainly not blind admiration, as the following quotes testify to.

> *"Most GPs don't know the symptoms of cancer." (F1)*

> *"My cousin had a lump on her head. She had been having headaches. The GP kept trying to give her one pill after another to try to treat the headache without trying to find the cause.." (F1)*

> *"They thought I had a virus." (F1)*

The above quotes illustrate what could be regarded as a growing sense of "realism" (or cynicism) directed at the medical profession, characterised by a critical awareness that doctors are able to make mistakes. The ideal image of the altruistic doctor (who deserves his power, wealth, and prestige) has also been shattered to a large degree. The quotes below effectively illustrate such feelings, and highlight the realisation among some, that high technology medicine can also simply be "fancy instruments".

> *"I changed doctors. All he was interested in was my money. He was involved in delving products and he wanted me to be involved in delving products.." (F1)*

> *"I am a bit sceptical. All these guys are in there for the money...This afternoon I had an ultrascan on my neck and what is the point. He will tell me it is cancer in the lymph node. These guys are so quick to come with a fancy instrument." (F2)*

Combine the above attitudes and realisations and one comes to the rather distressing conclusion that the patient is sometimes more qualified or skilled than the doctor at diagnosing pathology.

> *"My symptoms were itchiness...my doctor wasn't concerned about it...ENT specialist..gave me thorough examination. R450 later I was told there was nothing wrong with me... I even went to a skin specialist... I started reading through books on lymph glands... I told the doctor I had Hodgkin's disease." (F2)*

Ultimately, however, the doctor is the path to cure and as such must receive the respect of the majority of patients. Tishelmans and Sachs (1992) have noted, for example, how dissatisfaction with one's medical care is exceptionally difficult under circumstances of such dependency. When living with such a severe and stigmatised disease as cancer, one may find it essential to maintain a "blissful ignorance" or unquestionable faith in the expertise and good intentions of one's treating medical staff. It is such an adherence to what in many ways is an exceptionally traditional medical discourse, which could maintain a reasonable sense of order in a situation so marked by disorder (Tishelmans & Sachs, 1992). Such "blissful" faith in traditional authority figures is nicely illustrated by some of the qualitative responses to the survey questionnaire :

> *"I have a positive attitude and feeling about things, because I co-operate with the doctor and treatment and above all I am a Christian and I trust God for his will and his purpose in life."*

> *"I have complete faith and trust in my doctor and surgeon, as well as my treatment.."*

Tishelmans and Sachs (1992) found, however, that respondents in their sample expressed no interest whatsoever in psychosocial care or the services of a psychologist. To illustrate, they would receive typical responses such as the following:

"...but to tell the truth, I don't believe much in that kind of thing, I think psychologists are a little silly." (Tishelmans & Sachs, 1992)

Tishelmans and Sachs's (1992) study respondents instead explained that they received most of their support from close family and friends, with some explaining that they might see a social worker if it were really necessary. As has been clear, most respondents in this study agree with such sentiments. The task of this study, however, has been to investigate in more detail why such resistance is occurring. The clash between the individualistic and psychological discourse has been repeatedly emphasised in this regard, as have the various rhetorical strategies which maintain the dominance of the rational "I". A further significant rhetorical strategy, however, slots into the earlier discussed critique of professional authority.

> *"I feel that a psychiatrist would impose his own theoretical ideas on me, without having a clue as to what I am experiencing." (F1)*

The above quote illustrates the power of the individualistic discourse in claiming dominance of the rational "I" over mere "theoretical ideas" which are "imposed" by psychiatrists. The self is the rational, self-knowing "I" (repeatedly emphasised by this respondent) and as such is very firmly his - it is his experience, and as such cannot be subjected to external interpretation (by a mere theoretical body). The cancer experience is his; it is a subjectivity from which he cannot escape, and as such there is not only suspicion that a psychosocial professional would not be capable of understanding his experience, but there is the far more threatening fear that the psychosocial professional would position the patient in a subjectivity which has no respect for the practical "hard" reality of actually having cancer. The psychiatrist in this sense is unable to do justice to the personal cancer experience, of not being able to escape it, of being faced with the hard wall of this subjectivity where ever one may venture.

Some respondents, therefore, came to the rather radical conclusion that the psychiatrist with cancer would be the "ideal person." In this way both participants would be stuck in the same subjectivity; the playing field would be levelled, and thus enhance the potential to "relate".

> *"If a psychiatrist has been through it then he will be the ideal person. [Because he knows practically.]" (F1)*

> *"I don't mean all psychiatrists have to get cancer. If that psychiatrist got cancer somewhere in the relationship towards me as a patient he might get through to me. If that happens I can relate to him in the same manner." (F1)*

By knowing "practically" the psychiatrist might get "through to me" (to the "I") and thus "relate" in the "same manner". In a crude manner, therefore, the respondent is resisting the power and dependency inherent in the professional relationship. Where is the power though, the well-intentioned psychosocial professional may ask. The power quite evidently lies in the clash between the rational "I", the controlling agent of subjectivity, and the psychological psyche, the emotionally chaotic, out of control mind. The psychological psyche and the associated professional required for "clarification", is a direct threat to the hegemony of the rational "I", to his or her ability to claim ownership of thought, feeling, body, and ultimately, personhood. This, therefore, is the crucial difference between a 'mind' doctor and a 'body' doctor: A medical doctor takes care of the material body, something fundamentally separate to the rational "I", and as a result is not threatening to the rational "I". A psychological professional, however, asserts expertise over the rational "I" and transforms it into a psychologized psyche. I, as a conscious and rational being, become simply another medically scrutinised object, something comparable to the pancreas.

Note below how a respondent attempts to steer the 'problem' away from the mental/psychological domain to the "practical" domain of the cancer. The problem, and there certainly is one, is not a mental or psychological thing, but is the cancer.

> *"I read in the library books by journalist who had studied the medical field. If a psychiatrist had gone to that trouble and studied medicine and had almost done a thesis on what he thought the possible causes of cancer were and there was a talk on that then I would go see the psychiatrist." (F1)*

Such active attempts at reconstructing the psychological discourse (to the positively absurd) so that it "fits" (evens out the power slant) with the individualistic discourse appeared with regular frequency.

> *"If doctors and counsellors can be trained to be more down to earth you will trust them more." (F1)*

Although no clarification is given as to what "down to earth" might mean, the basic message of the statement is clear; - help me practically and stop messing with my mind, help my "I" instead of confusing it.

Although the cancer certainly is the problem, other respondents felt that psychosocial care should not always drum home the cancer message.

> *"They should offer us some other kind of incentive other than cancer like a walk." (F2)*

In this regard one could interpret it as a resistance to the victimising role of being a cancer patient. As discussed, medical staff are essential to combat the disease, and are thus tolerated and praised. Such a physical preoccupation in any case is of little threat to the rational "I". The psychosocial professional carries a discourse which is profoundly threatening, however, and as we have seen is thus steered away (reconstructed) to more "practical" and "down to earth" domains such as the cancer itself. The question immediately follows, however, why such "psychosocial" professionals would be necessary if all they occupy themselves with is the cancer (the medical staff's domain). Some respondents, therefore, attempt to destroy the very professional nature of the psychosocial discourse, turning it into everyday, normal, and natural interaction and activity. Note below, for example, how a respondent interviewed immediately after he consulted a psychiatrist, "normalised" (de-professionalized) his experience.

> *M: "You have just seen a psychiatrist. How does it make you feel?"*
> *"Normal. It is like talking to you about the same thing." (I2)*

Presented with such an account, one is tempted to ask why he bothered seeing a psychiatrist.

The actual "product" at the end of the day is of course not resisted. Whether one is positioned in the individualistic or psychological discourse, it is difficult to disavow the utility (or necessity) of meaningful interactions with other human beings. It is this commonality which appeared to motivate respondents' attempts at reconstructing the psychological discourse (instead of throwing it, and the whole system of psychosocial care, out). Note below how a "homely" sense of "normal", and essentially warm, human relating is searched for.

> *"I find Mowbray [CANSA head-office] is very cold. I can't relax there. We sat around a big table once and we watched a movie. I didn't go again. There was no place whereby they said 'come pop in and chat.' It is nice to meet people with cancer." (F2)*

> *"I wouldn't come to a place like this because it is not homely."*
> *M: "How about if someone said 'come around for an evening for a glass of wine' but so that you know everybody has cancer?"*
> *"That is okay." (F2)*

It has been made clear that the clash between the individualistic and psychological discourse pivots around notions of personal control. The mind under influence of various independent psychic forces, and the body of expertise and experts such an understanding carries with it, are a direct threat to the rational and conscious personal control of the "I". It is a direct threat to the individualist's sense of personhood (it contradicts the very idea of being a person - a rational and conscious one). Although the above section has presented in many ways a conglomeration of various strategies aimed at protecting this sense of personhood, they do all at a certain level form part of a general strategy of de-professionalisation. In all the above cases an attempt is made to destroy the notion that a body of expertise and experts are required to deal with the "mental" or "emotional" domain, - without rejecting the utility of meaningful human relating. The cancer experience is "my" experience, and thus falls under the auspices of the rational "I". Certainly there may be distress, but again that is "my" distress which ultimately is no threat to the sense of personhood, - it will be dealt with either privately, or with people "I" can trust and relate to on a relatively equal level. The very idea that a professional or expert might be necessary threatens this entire conceptualisation of the self and its place in the world.

Emotional chaos: The wounded animal

People with cancer do get distressed. This is a well documented fact also admitted by most people with cancer, no matter how individualist their orientation may be. Besides the earlier discussed "battle wounds", however, there are also times when the person with cancer feels emotionally lost and chaotic, a state which in many ways threatens the power of the rational "I". In this study several respondents described such moments of "not knowing what is happening". It might be argued that in such situations the psychological discourse would become of undeniable relevance. If one feels that one is "losing it", that one is in dire need for some sense of clarity or order, surely then a psychosocial professional would be an option?

> *"Maybe I needed a push or a more personalised introduction to it. You go through phases of depression. It is too terrible. When you know why you are depressed you can always handle it. When there is this general cloud of depression that hangs over you, you know it is because you are ill, but you might feel you are going to die. Do you feel you are going to be all right? What do you feel it is going to do this to the family? You have got all these things going on in your mind. There are other times when it has got nothing to do with your illness, you just feel depressed." (I1)*

Note above how this respondent, with hindsight, felt she might have needed professional help, since there were times when she could not attribute the depression to any rational reasons. Such psychologization of the past did occur quite frequently in the focus groups and interviews (see below), but little indication was given as to how people might construct their experience at the actual time of distress, a construction which prevented them from seeking professional help. One possible way was illustrated by the respondent below in an individual interview.

> *"You feel at times like a wounded animal and what a wounded animal does is that it goes into a corner and it just lies down and wants to be left alone. You get those feelings. There were times when I just wanted to be left alone. Perhaps when I recovered I should have gone a support group." (I1)*

Here the respondent constructs her experience using a creative analogy. Like a wounded animal she wanted time alone so she could "lick her wounds" in private. Aspects of the individualistic discourse are thus expressed in the way she felt the need to deal with her suffering alone, to face it as a being living in the tough animal world would. Note how she qualifies this response by reflecting psychologically on the experience, suggesting that she might have benefited from a support group *after* the main period of suffering. Besides the obvious question of "why then", when she had "recovered" already, it was also noteworthy how she selected a less professionalised form of psychosocial intervention (resisting the psychological discourse). Being challenged on this response, she outlines first the hierarchy of professionalism (and the concurrent descent into destruction of the rational "I").

> *M: Not a psychologist?*
> *R: "I don't know. I would have started with a support group. If that hadn't helped me I would have gone to a psychologist. If that hadn't helped me I would have gone to a psychiatrist." (I1)*

At this point in the interview I assumed she was attempting to de-pathologize (de-professionalize) her experience and thus tried to 'help her along' as it were, clarifying what she was 'actually' attempting to say (possibly culminating in an interest in less professionalised services such as support groups). Up to this point in the interview, the respondent had made liberal and sophisticated use of the psychological discourse, making sense of her own (past) experience, and the supposed benefits of psychosocial care. On being confronted by a personal (although mild) positioning in this discourse (led by her own trail of reasoning), note how the flow of discourse is abruptly altered; - the psychological discourse self-destructs and the rational "I" cries out desperately.

> *M: "So a support group is softer in a sense. It doesn't have the connotations of 'I am ill, I need treatment.'"*
>
> *R: "I just felt I had cancer, I was having treatment. I didn't feel well. I didn't feel like going along to a meeting hearing about other people's ailments. It was too much." (I1)*

The above slice of discourse offers a possible understanding of why people with cancer are resistant to using psychosocial care, even when some of these people are reasonably familiar with, and sympathetic towards, the psychological discourse. So far a description has been provided of how respondents manage to use both an individualistic and psychological discourse, and how the psychological discourse is repeatedly reconstructed so that it "fits" the individualistic framework. Ultimately, however, this is talk from the comforts of hindsight. Respondents were able to reflect on their experiences from a position of relative wellness (although some of the respondents scored "depressed" on various rating scales none showed any signs of serious distress at the time of interview), and thus could sit back and "play" as it were with the psychological discourse. The piece of conversation above, however, suggests that under times of serious distress no such room for "play" is available, and that the rational "I" is fighting a bitter battle for survival. In other words, it is suggested that under times of distress, the very time when help seeking behaviour should be motivated, is exactly the time when the rational "I" is most stubbornly clinging onto a notion of rational and moral victory. It is the time when the person with cancer is so desperately hanging onto a sense of personhood, a sense of being alive, that he or she is vulnerable to "losing touch with reality" and thus slips into what the psychological discourse calls "denial."

"I tried to be tough and strong": psychologize the past

Although the individualistic discourse was clearly dominant in nearly all discussion in the research, the psychological discourse did make its presence felt at times, and most prominently so when talking about the past.

> *"I can't say exactly why I didn't use a support group or a counsellor. Maybe I tried to be tough or I felt I couldn't handle it. You do get a lot of people like that. Some people think 'I don't need anybody else to tell me what to do...'" (I1)*
>
> *Coping course: "I never went to that. I should have gone. Perhaps if I had gone to that I would have found it very beneficial and maybe it is excellent, I don't know. I didn't go to anybody."*
> *M: Why didn't you go?..*
> *"I just thought I was handling everything all right."*
> *M: You don't think you could have benefited more if you went to one of those courses?*
> *"Yes, looking back now I think I should have gone."*
> *M: What were you thinking at the time?*
> *"I think I had the little bit of the attitude 'I don't need to go' that I could cope. I think I was trying to prove too much how strong I was. One does that. You try and prove how strong you are, you try and prove you can fight it, you try and see how you can handle things very well." (I1)*

It can be assumed that the context of the interview or focus group situation, including my presence as symbol of the psychological discourse, exerted a certain pressure on respondents to make sense of this discourse. In the above piece of conversation, for example, the respondent appears to apologetically "confess" to having utilised an individualistic discourse (an "I could cope, I tried to be tough" attitude). She reflects on her experience utilising a psychological framework and thus emphasises the stupidity of the macho "I". Such reflection and cross-referral to contrasting discourses illustrates the incredible flexibility with which people are able to narrate and re-narrate their experience. A slice of conversation such as the above, divorced from its context could lead one to assume that all that lies behind the resistance towards psychosocial care is a self-confessed and silly macho attitude. Such is only a rhetorical device, however, which appears to function only as an appeasement, a temporary deference towards the sophistication of the middle class psychologized life. Underlying it lies the incredible scope and power of the individualistic discourse, which ultimately is embedded in nearly all of Western society's prominent institutions.

The role of practical reasons

Some respondents emphasised various practical reasons standing in the way of psychosocial services use.

> *"Financial levels within families are very challenging. If you mention the word psychologist/psychiatrist the first thing that comes to mind is the expense. It is out of my reach. Those are the things that play a role." (F1)*

Also in the questionnaire survey, factors such as service fees, transport costs, and time factors were mentioned. Although such factors certainly are relevant, it is debatable whether they are *the* factors standing in the way of popular utilisation of psychosocial services. Rather, such reasoning must be understood in context of what the system of psychosocial care purports to offer, and what the intended recipients understand it as offering. In other words, the problem must be understood from a cost-benefit perspective.

The psychological discourse proper, as has been discussed, carries with it a body of expertise and experts. The professional relationship is emphasised since one is dealing with an area of medical and scientific concern. As such it does to an extent align itself with medical practice, in the sense that psychological "morbidity" is targeted with "interventions" so that "mental health" may result. As such, practical issues should not be a major concern, since one does not generally question the necessity of "health". Just as even the poorest seek medical help (although they do to a lesser degree than the rich), so they should seek psychological help.

The intended recipients make sense of their lives using an individualistic discourse, however, and as such construct the psychological domain (including the professional system) as either referring to extreme pathology or madness, or as a 'cultural' whim or trend. As such, psychosocial care is either perceived as profoundly threatening, or as rather arbitrary and inessential. Any benefit inherent in psychosocial care is deconstructed to ordinary, every day type human interaction, no different to friendship. Why bother with psychosocial care therefore? Why use two valuable free hours a week to participate in a support group, why spend time and money transporting oneself to the venue, or why pay someone money just to *talk* to that person (pull out a fancy instrument and the situation might be different)? Why do all of that if all that follows is an oppressing gaze eating away at one's sense of personhood?

5. THE PLACE OF THE VARIOUS TYPES OF PSYCHOSOCIAL CARE

The above discussion dealt with the two prominent discourses and the various rhetorical strategies used to affirm dominance of the rational "I". Psychosocial care was roughly placed within the psychological discourse in this regard, without paying much attention to the differences between the various types of intervention. Respondents did distinguish between various types of care, however, distinctions which in turn slot into the discursive framework discussed above. As such, a more detailed outline of the way the various types of care were discursively constructed shall now be provided.

Psychiatry

Talk revolving around psychiatry expressed the strong pathology associations with this discipline.

> *"There is a need for psychiatrists. If your mental state is in a situation where you can't solve it yourself and you are mentally screwed up the only course open is a psychologist/psychiatrist." (F1)*

> *"To be in a situation where you have so much stress where you feel you will commit suicide a psychiatrist will be necessary." (F1)*

The quotes above illustrate the belief that psychiatrists are for people with serious psychopathological conditions - very specifically, disorders of the mind - where chaos and madness reign over rationality and freedom. Psychiatry therefore symbolises the ultimate destruction of the rational "I", the total destruction of rational consciousness and personhood. Such a scenario can therefore be exceptionally threatening to some:

> *"I didn't regard myself as a capable person getting through this but my husband refused point blank to see someone. As far as he was concerned you had to come to terms with it and find a solution yourself. Psychiatrists have bad connotations for him." (F1)*

Note how the female respondent needed to 'confess' that she was not a "capable person" in order to justify her willingness to see a psychiatrist - she sacrificed her rational "I", something her husband had no intention of doing.

With regard to cancer, respondents had difficulty understanding what a psychiatrist could possibly contribute to. Such a professional is too theoretical and mind orientated to have anything meaningful to say about the cancer experience.

"I feel that a psychiatrist would impose his own theoretical ideas on me, without having a clue as to what I am experiencing." (F1)

"My mother is a social worker so she also works with people who get cancer. I can speak to her, but speaking to someone who hasn't had cancer doesn't know what I am going through."
M: "So you feel a psychiatrist wouldn't have a clue?"
"They can say 'shame' but they don't know. It is better to speak to someone who has been there. [I agree]." (F1)

Strong resistance is thus expressed from the individualistic perspective, by claiming ownership of one's experience and rejecting the theoretical imposition of an alternative interpretation. As a result, some respondents attempted to level the playing field according to individualistic discourse ground rules:

"If a psychiatrist has been through it then he will be the ideal person. [Because he knows practically.]" (F1)

The psychiatrist nevertheless is an expert on mind, with medical authority, and as such receives recognition of this fact.

"..He understands on the medical side and he understands on the emotional side.." (F1)

"The psychiatrist has studied more so he would probably help you more than a counsellor." (F1)

From the psychological perspective, with its emphasis on emotional expression and clarification, such an expert could obviously come in useful.

> *"I think it would be quite comforting because you can so often open up to a stranger than you can to a family. One feels that you can express your personal feelings, your emotional feelings and your physical feelings to a psychiatrist..." (I1)*

> *M: How did you land up there?*
> *"It is possible to maybe have some of my own emotions explained. One does get very mixed up and not knowing how you feel." (I1)*

Counselling

Whereas a psychiatrist or clinical psychologist would deal with serious <u>mental</u> problems, a counsellor is more practically orientated, dealing with more 'down to earth' or cancer-specific problems.

> *"A psychiatrist is a man who deals with people who have mental problems and a counsellor is a person who has a more down to earth knowledge of what is going on and is not specifically geared toward to the schizophrenic or the mass murderer. A psychiatrist is more like a specialist. The people who work for LifeLine are counsellors." (F2)*

As the above quote illustrates, a psychiatrist is a serious "man" (note the gender construction) who deals with extreme forms of madness and criminal deviance, whereas a counsellor is a more informal 'down to earth' type helper. As discussed earlier, respondents used both an essentialist (psychology as deep pathology) and a normative account (psychology as cultural whim) in protecting the individualistic discourse. Psychiatry, in this regard, slots very evidently into the pathological account, in effect banishing it to the depths of unimaginable chaos.

A counsellor, on the other hand, is not as stigmatised and threatening, and as a result has a "softer", less intimidating feel to it.

> *"I think the word counsellor has a softer, more emphatic feeling to it." (F1)*

> *"I would rather go to a counsellor than a psychiatrist." (F2)*

Although less pathologically marked, the counsellor ironically suffers from a lack of expertise. The very trademark of the psychiatrist or psychologist is emotional expertise (which in turn necessitates destruction of the rational "I", i.e. madness). A counsellor, however, is not as 'deep', and although therefore not associated with destruction of the rational "I", is ironically rather arbitrary (back to the normative account).

> *"A clinical psychologist has also perhaps got a deeper understanding of different emotions to an ordinary counsellor." - (I1)*

> *"The psychiatrist has studied more so he would probably help you more than a counsellor." (F2)*

The hierarchy runs across several axes therefore. The rational "I" to pathological mind continuum is linked to a legitimate expert to lay helper continuum, which in turn is linked to a medical necessity to cultural whim continuum. Wherever the psychosocial professional moves, he or she is positioned out of relevance.

When it comes down to actually consulting with a psychiatrist or counsellor, the theoretical differences furthermore stop, since all one is left with is ordinary conversation between two people. The individualistic discourse ultimately deconstructs the essential 'professional' character of such relationships, and thus places them on the same level as ordinary relating.

> *"They are all the same. They say the same sort of things." (F1)*

Coping skills courses

A coping skills course, and more specifically the 'I can cope' training course, carries with it the message that such courses are for people who are *not* coping. In other words, coping courses are for people who have lost their individualist battle with cancer.

> *M: "The cancer association has an 'I can cope' course. Have you heard of it?"*
> *"No."*
> *"I am not interested."*
> *M: "What puts you off?"*
> *"Because I am coping as I am. Why should I be with more people who have the same troubles as I? I will hear more sorrow. I can cope. They are there for people who can't cope." (F2)*

The above respondents presented this argument immediately after he consulted with a psychiatrist (as part of another study). Although he claimed he was 'fine' he did at initial assessment several weeks earlier 'confess' to severe psychological distress. Such examples illustrate the strength of the individualistic discourse, in the way it motivates resistance towards psychosocial care, often resulting in the well-documented phenomenon of 'denial'.

The idea of being 'trained' to cope also clashed with the basic tenets inherent in the individualistic discourse. How an expert could possibly have anything meaningful to say about one's private suffering and grief (which needs to be faced with courage, strength, and faith) was beyond most respondents.

> *"I don't think a course would do anything (agreement)." (F2)*

Although most respondents did affirm the various benefits inherent in fellow patient support (see below), a substantial number did express a dislike of group situations. Some respondents, in particular, did not see the point of 'wallowing' with other troubled people.

> *" Why should I be with more people who have the same troubles as I? I will hear more sorrow." (F2)*

The individualistic dictum of dealing with one's suffering on one's own clashed with the idea of 'sharing' one's problems with others.

> *"This I can cope course at the beginning, even though that is when you need to learn how to cope, you are still trying to cope with it and find yourself. You are very reluctant to go out there to share your struggle with others. [It is better now (when over the worst) to go and do that course.]" (F1)*

The above piece of discourse illustrates the constant flipping back and forth between a individualistic and psychological discourse. On the one hand she confesses to needing to 'learn how to cope' and affirms the benefits inherent in 'sharing your struggle with others'. Nevertheless, she qualifies this statement by emphasising the need to 'cope with it and find yourself'. The first priority is claiming a victory for the rational 'I', proving to oneself that one has 'coped', that one is still in some sense a rational being living in a morally and spiritually meaningful world. Once that has been accomplished it could be possible to 'do that course'.

As discussed earlier, in some cases the psychological discourse can reign completely - when constructing one's past behaviour. When put under pressure by the psychological 'disciplining' gaze, note how this respondent refers to the individualistic discourse using a 'psychological' interpretation.

> *"I never went to that. I should have gone. Perhaps if I had gone to that I would have found it very beneficial and maybe it is excellent, I don't know. I didn't go to anybody."*
> *M: Why didn't you go?..*
> *"I just thought I was handling everything all right."*
> *M: You don't think you could have benefited more if you went to one of those courses?*
> *"Yes, looking back now I think I should have gone."*
> *M: What were you thinking at the time?*
> *"I think I had the little bit of the attitude 'I don't need to go' that I could cope. I think I was trying to prove too much how strong I was. One does that. You try and prove how strong you are, you try and prove you can fight it, you try and see how you can handle things very well." (I1)*

In the above case, the respondent freely admitted that she was captivated by the individualist pressure to 'fight' and 'prove how strong you are'. In other words, she confessed to having experienced the world through the frames of the individualistic discourse. Using the comfort of hindsight, however, she is able to psychologize that past, claim intellectual sophistication, and brush the individualistic dictums off as rather silly. The catch is, off course, that now she can quite comfortably argue that she does not need psychosocial care because she is currently doing 'fine'.

As discussed earlier, the actual 'product' is not the problem - people appear to believe in the benefits inherent in meaningful human interaction, whether one sees it from a psychological or individualistic perspective. As such, a coping course could be useful when feeling lonely or 'isolated'.

> *"If I needed to be with people who had cancer and were coping I would go there so I didn't feel isolated." (F2)*

But if such everyday type interaction is all a coping course can offer, is it worth the practical costs (transport, fees, commitment)? Perhaps not, as the following suggestions seem to allude to:

> *"Maybe they should make it shorter." (F2)*

> *"If they advertised it more people would be interested." (F1)*

Support groups

> *M: "Who do you think goes to support groups?"*
> *"Someone who is feeling lonely, somebody not coping well or they haven't got family support." - (I2)*

> *"I have never been to a support group. I imagine a support group would be like what AA has." (I2)*

The above quotes illustrate that the very term "support group" is firmly placed in the psychological discourse, and thus is inevitably associated with the pathologized (and thus destroyed) rational "I". People who go to a support group very definitely have a problem of some sort, more often that not a problem 'inside their head' (such as not controlling their drinking - the AA support group prototype). The dominant rational "I" will thus resist being positioned into a situation of threat.

As shown by the survey, most respondents felt that they received a great deal of social support from their family, friends and doctors. Such sources of support, as discussed, are 'natural' sources of support, which slot harmoniously into the individualistic discourse (i.e. they do not threaten the survival of the rational "I"). It is thus not surprising that most respondents in the focus groups and interviews, reacting to the concept of support groups, argued that they "had all the support they needed".

M: "What about support groups?"
"I feel I don't need it. I have got family support which is more important." - (I2)

"I have got my family so I don't need a support group."
M: "Do you think a support group is a good idea?"
"Yes."
M: "What happens if you didn't have a family."
"Then I would look at a support group." (I2)

"I do have good friends and family. I did have the support I needed. In the light of that I felt I didn't need support groups. I didn't look for anything. I know they do have something advertised at Groote Schuur in the cancer department if you need help. I went to the Cancer Association to get booklets to read up on my particular type of cancer and I know I could have spoken to them so I knew that was available. Maybe if had been a woman on my own without the family support and friends I had I would have needed that very much. I didn't really need it so I can't judge if there is enough out there for cancer people or not." (I1)

The quotes above illustrate the primacy of family and friends as sources of support, since such relationships are somehow more 'real'. Only if 'real' sources of support are inaccessible will a support group become a (poorer and intrinsically different) alternative.

M: "Do you think a support group can replace the support of the family or do you think they are something different?"
"Something different. I think you need something like that to find out about your sickness."
"With your strangers they first have to become your friend. Your family reaches much deeper." (F1)

The above quote again emphasises the primacy of natural support, but also gives an indication of how a successful form of psychosocial care is conceptualised by these respondents. The respondent argues that "strangers they first have to become your friend", - in other words, the support group must become, over time, a 'natural' form of support, a place and occasion where 'friends' meet and support each other.

Such resistance towards the psychological discourse (professionalisation, expression of emotions, etc.) qualified by an affirmation of the benefits in meaningful, 'real', and 'practical' human relating, was expressed by various respondents in various ways:

> *"A support group is a very good idea. There are people out there who really love, care, and understand. A support group is not so artificial." (F1)*

> *"I didn't go to a support group. I am a private person and I prefer to keep it that way. My mother-in-law had cancer and she went to a church group. Her church fellows were tremendously supportive of her and I think she got tremendous encouragement and strength of having wonderful ladies around her. They cooked and drove her around. They were little things but they all add up." (F1)*

Note above how the latter respondent positioned herself out of the psychological discourse by claiming a 'privacy' orientated personality trait (resisting the 'superficial' expression of emotion to strangers). She qualifies this resistance by presenting a more 'natural' and 'practical' scenario where the person received "encouragement" and "strength" from "church fellows", and where the value in the "little things" were clearly apparent. A scenario was painted, in other words, which slotted harmoniously into the individualistic discourse.

The focus groups, at a practical level, presented a support group type scenario, with the result that several respondents reflected on this group experience.

"Something that struck me this evening is what we have all enjoyed doing or wanted to do is relate our stories. That in itself is therapeutic. It is not always appropriate to do that. So in a sense a support group could be beneficial." (F2)

"It was so evident in this group that we wanted to share our experiences. [You don't normally do that.]" - (F2)

The above quotes reflect the results of the questionnaire survey, in the emphasis they put on the "relating" of "stories" and the "sharing of experiences". Although in some sense resembling the psychological dictum of emotional expression, it appears that such sentiments slot more into an individualistic/common-sensical notion of 'camaraderie' than any theoretical notions in the psychological discourse. The positive attitudes expressed towards fellow patient support and the general dominance of the rational "I" lends support to this argument. A support group is characterised by fellow patient support, and as such the 'relating' occurs between people with similar experiences.

M: "So you would prefer a support group to a counsellor?"
"It comes back to the fact that also knowing that other people understand what you are going through." (F1)

A relationship based on such equal terms offers camaraderie, or more specifically, the opportunity to *legitimise* and *normalise* one's feelings and experiences.

"They can't always give you all the answers. But it is very nice to go along to one of these and you are voicing your feelings and hearing someone else expressing the same sort of feelings. This helps one. You don't feel so cut off. You don't feel any different. You feel 'this is the normal thing to happen, this is okay'. You don't make an issue of it, it is within yourself." (I1)

> *"One goes through all different sorts of feelings. There was some picture on the wall downstairs in the blood section and I read it. It said 'you feel different emotions: anger or disbelief'. You do go through all those emotions. I have been going through those emotions. Reading it there I felt normal. I felt 'this is what other people are feeling.' I didn't feel so alone. I felt 'others understand; they know, my feelings are normal.' This is where a support group does help. A lot of the emotions and feelings you are experiencing you think only you are feeling them but they are normal and natural feelings. An ex-cancer patient would understand it or somebody trained. It is a natural and normal feeling to experience when you go through this that you are alone. Until I read that there I thought it was only me feeling these feelings. I was pleased to read that. That is what I probably would have gained by going to a support group. I would have gained that information earlier and thought 'I am not different from anybody else. They also feel that way'. It is quite natural to feel like that." (I1)*

The quotes above illustrate how the sharing of similar experiences can lead one to the conclusion that one's feelings are "natural" or "normal". The "therapeutic" effect, therefore, has nothing to do with understanding the unconscious forces lying at the root of one's rather chaotic feelings (the psychological discourse), but is all to do with the normalisation and legitimisation of *my* feelings. My feelings, although distressing, are still my feelings; - they are normal, natural, and therefore legitimate - and thus not open to re-interpretation or "treatment".

The concept of a support group, although rooted in psychological discourse, is thus amenable to re-interpretation (re-construction) using the individualistic discourse. The professionalised (pathologised) discourse is rejected, and instead emphasis is placed on comradeship, "encouragement" and "morale boosts" (not "support"), and the legitimisation of *my* feelings (as opposed to the pathologising or psychologising of feelings). Using such rhetorical strategies the support group is re-constructed into a more 'real' social encounter, with somewhat political overtones.

However, by deconstructing the professional 'frame' to ordinary, everyday type interaction it inevitably falls pray to the same factors limiting everyday type 'relating'. In South Africa, the legacy and reality of diversity is a prominent factor.

> *"Sometimes with all due respect to everybody, when you go to the cancer clinic you have a very mixed bag of people from all walks of life. Sometimes to get people together from a similar background is advantageous. I could say to so and so 'my husband took me here and friends did this' and I am in a room with very poor people who don't have a husband to take them anywhere, who don't have friends to take them anywhere and you feel awful. It is sad. Whereas they perhaps can't relate to me in their emotional feeling. They should get similar groups together." (I1)*

> *"I don't think it will work in South Africa."*
> *M: "Why not?"*
> *"Because of our ethnic groups and the language problems we have. Some people haven't got time to do it." (F2)*

The notion of a support group certainly sits squarely on top of the various dilemmas between the individualistic and psychological discourses. In one sense, the very term 'support group' and its institutional background and history, imply various forms of the destroyed "I". The support group attendant is perceived to be a lonely unfortunate who is unable to cope and thus needs a "psychological intervention" of some sort. At this institutional level of discourse (the fact that a support group has a history associated with examples such as AA, and is offered by professional institutions - such as CANSA), the rational "I" is forced to reject support groups for self-preservatory reasons. To attend a support group is an admittance of defeat, a moral failure.

The fact that support groups operate primarily through fellow patient support offers a way out, however, and probably explains the relatively high interest in self-help groups observed in the survey, as oposed to professionally run support groups. Respondents were able to reconstruct the notion of support groups so as to strengthen the validity of the rational "I". 'Real' relating between participants can take place because they have all had similar experiences. 'Encouragement' and 'moral' support can be exchanged, and perhaps most importantly of all, the ultimately private experience of suffering and emotional chaos is legitimised and normalised, instead of pathologised and professionalised. This to a large extent seems to explain the difference between self-help groups and professionally run groups. Professionally run groups, at heart, are still professional services (concerned with therapeutic and clarifying aims), whereas self-help groups revolve around the legitimisation of 'my' feelings.

Patient visits

The concept of patient visits was subjected to similar rhetorical strategies as the concept of support groups was. On the one hand, a visit by a veteran patient is rather artificial and absurd (in terms of the individualistic framework), and thus is difficult to take seriously.

> *"RfR came to visit us and it was really a joke. I was trying to be serious. She said she also had cancer and she could pick up her arm and with this she took out a prosthesis which was warm still from her body and she 'here.' None of us wanted to hold it. We laughed so much that the sister had to tell us to shut up. At that time you are quite hysterical..If you don't laugh you will go crazy....But she did her job well and it was kind of her to come because maybe none of us would have known what to have done and if you were stuck for a boob you could always go and find one where she was...It was lucky we could laugh about it otherwise we would have cried. It is like when you go to a funeral and you laugh." (F2)*

As mentioned by the above respondent, the notion of patient visits can nevertheless not be rejected outright, since even within an individualistic framework they could still be useful. Personal and practical information is not only useful, but also eases some of the anxieties about what lies ahead, and normalises one's own sometimes chaotic emotions.

M: "In the questionnaire you mentioned that it would be a good idea for a veteran patient to visit a new patient. Is that a good idea?"

"Yes, it let's new cancer patients know how the others coped with the pain and sickness. I spoke to one or two on a long term basis. It is good to know what they went through. It is nice to know how long they have had treatment for, what type of cancer they had and where they had it." (I2)

"My friend's husband got cancer a while back and all I could do was tell him that if he felt this or that he shouldn't be alarmed, it is normal. He was very grateful to me for telling him that. He had to go to be measured by the radiologist and I explained that to him which was a help. In that little way it helped him. His wife told me he was complaining of tiredness. I spoke to him sternly and said 'you must listen to your body. That is what the doctor said. If you feel tired be tired and relax. Don't feel guilty about it', which was some of the emotions I went through until the doctor said to me 'listen to your body.' I always felt guilty because I wanted to rest or sleep. That is how I helped him. Little things like that can help." - (I1)

6. THE ROLE OF FELLOW PATIENTS: THE WAY FORWARD?

The results of the questionnaire survey showed that respondents were amenable to the idea of fellow patient support. The relatively high interest in the least professionalised psychosocial services affirmed this theme. In the previous discussions I alluded to the idea that respondents are only rejecting the psychological discourse because it threatens the dominance and survival of the rational "I". In other words, only the professionalised and pathologised discourses are rejected - not the actual base idea of meaningful human interaction. Within the individualistic discourse, such 'real' human interaction is furthermore 'natural' and/or 'normal', if not essential.

Although such 'real' relationships occur most frequently between family, friends, religious fellows / priest, and sometimes one's doctor - only 'natural', rational, or traditional links - they can also occur between people who have encountered (or endured) similar experiences. Fellow patients can, according to respondents, fulfil several functions, which, in contrast with most forms of psychosocial care, do not appear to threaten the rational "I".

> *"I had two friends (they weren't close friends but good acquaintances) who had gone through treatment and had finished treatment and they were very good to me. They told me what would happen when I went to Groote Schuur, what would happen when I went for the measuring up for the radiotherapy and I found this so wonderful because as I walked in there I knew what was going to happen....It was just explaining certain things which I found easier to handle...Just having the information helped me." (I1)*

As the above respondent explained, insider's information about the procedures can ease anxieties and feelings of uncertainty. It appears that such information is especially useful and powerful since it comes from people who have gone through it - in other words, it is in some sense more 'personal'.

The fact that the other person has experienced similar problems is an immediate and 'natural' link, a link which alters the very character of the relationship. Note how the respondents below metaphorically (and humorously) intensifies the relationship with her friend.

> *"A friend of mine was diagnosed with cancer a month before I was and her drain also came out. She was a week ahead which helped me tremendously because I knew what was going to happen....We compared notes...I said to her she was really my bosom friend now because 2 breast casts were next to one another." (F2)*

According to most respondents, people with cancer need to "relate" or tell their "stories". Although similar to the psychological perspective on "emotional expression" it cannot be placed in this category because no professionalised interpretation is desired. Such relating of stories can occur between fellow patients because people approach each other on equal terms. One is simply telling one's story to others who have experienced similar things.

As a result no sympathy (from family or friends) is expected, and neither is any professional interpretation or advice expected.

> *"Something that struck me this evening is what we have all enjoyed doing or wanted to do is relate our stories. That in itself is therapeutic. It is not always appropriate to do that. So in a sense a support group could be beneficial." (F2)*

> *"I went to this other chap because he also had lymphoma. I knew then he wanted to talk."*
> *M: "Was it nice talking to him?"*
> *"Yes. You are there for somebody else and you start relating your story. I can talk about my cancer openly." (F2)*

Ironically, it is the fellow patient friendship which ultimately provides the 'non-judgmental' and 'non-threatening' environment required for emotional expression. It is such not because of professional neutrality or distancing, but because each party can understand the other's pain.

> *"What I found the most therapeutic was going to a friend who had the same as I and we just cried." (F2)*

The primary reason such intimate 'relating' is possible, is the fact that both participants have experienced similar problems and feelings. As mentioned, this is the vital ingredient which makes camaraderie and 'true' understanding possible.

> *"My mother is a social worker so she also works with people who get cancer. I can speak to her, but speaking to someone who hasn't had cancer doesn't know what I am going through."*
> *M: "So you feel a psychiatrist wouldn't have a clue?"*
> *"They can say 'shame' but they don't know. It is better to speak to someone who has been there. [I agree]." (F1)*

When living within an individualistic framework, nobody, except the fellow sufferer (or the ever loyal family member or friend), can possibly do justice to the very personal experience of having cancer. One is inscribed by a cancer discourse resembling a prison, and no escape is possible (except through cosmic or medical intervention). Only the rational "I" is left which must accept the 'reality' and face it with courage and dignity. Only here lies any sense of freedom, and ultimately victory, since one can choose, and thus succeed in facing one's fate with courage and dignity (whether one lives or dies). The psychosocial body of experts and expertise is a threat to the freedom and dignity of the rational "I" since they bring with them the implication that the "I" is not quite so rational, in control, or sane as he or she might assume. Such a discourse thus threatens the 'reality' of one's experience, and thus ultimately the meaning inherent in it.

Fellow patients, however, can understand the 'reality' of the experience since they have also experienced it. As such they are able to do justice to the experience, normalising and legitimising it, so that it is after all 'real'. The rational "I" is left intact.

> *"One thing I did find was during treatment and just after. one of my symptoms was a very dry mouth and it woke me up at night. You don't appreciate the saliva in your mouth until you haven't got it. Just going for a check up one day there was a young chap who used to go for radiation at the same time as me and I hadn't seen him since we had both finished our treatment. Seeing him there was like seeing an old long lost friend. I asked him how he was and he said he had a terribly dry mouth that was driving him mad. I told I was pleased and he asked what I meant by that. I told him I had that too. I hate talking ailments to friends, I find it terribly boring but sometimes when people have gone through the same thing and they say 'I found such and such' or 'emotionally I feel this', you realise you are not alone." (I1)*
>
> *"The other thing that helps is knowing that you are not the only one. There are others who have been through it as well." (F1)*

When speaking to fellow patients one is furthermore provided with different perspectives and thus different options on how to go about dealing with one's situation (suggestions coming from people who have been there!).

> *"Chatting to somebody else helps. Sometimes if you have more than one person, one will bring up something that sparks off a thought or an idea/feeling that the next one might have. This is where it is an advantage. Only good can come from speaking." - (I1)*

Contrary to the professional services, the base notion of fellow patient support appears to be an amenable option to the rational "I". I have argued that the whole issue pivots around the protection of the rational "I", and the 'reality' of 'my' experience and suffering. Whereas a psychological/professional discourse threatens this sense of realness and concurrent moral victory, the fellow patient is, on the other hand, able to legitimise and normalise one's sometimes chaotic feelings. One might be stuck within a world of cancer, but 'I' am still 'me', and can decide how to face 'my' suffering and pain - it is this type of reasoning which leaves the sufferer with a sense of personal control, a sense of still being a rationally free person, or in other words, a sense of still being alive.

> *"I was conscious when I had chemotherapy that all the people who had chemotherapy were so happy. To get the vibe of the fact that you are still living and you are still alive and things are carrying on lifts you." (F1)*

CHAPTER 6

CONCLUDING DISCUSSIONS

1. A SUMMARY OF RESULTS

This thesis has attempted to accomplish two tasks. At one level it tried to provide some explanation as to why people with cancer resist various forms of psychosocial care. At another level, however, it has attempted to challenge the seemingly straightforward relationship between psychosocial oncology, psychosocial care, and the person with cancer. How should we understand the person with cancer, and how is he or she reacting to the statements coming from psychosocial oncology and psychosocial care? In other words, how is the person with cancer reacting to our academic and professional attempts at understanding (and helping?) the person with cancer?

Psychosocial oncology informs us that a significant proportion of people with cancer experience significant levels of psychological distress. Such was made clear in chapter 1. The discipline has also shown, however, that various forms of psychosocial care can alleviate such psychological distress. Halfway through chapter 2, therefore, the relationship seemed quite clear. People with cancer suffer from 'psychosocial problems' and various forms of 'intervention', 'treatment', or 'care' are available to alleviate such 'psychosocial problems.' People with cancer should, logically speaking, be utilising such services.

Serious criticisms have however been levelled at the system of psychosocial care, putting into question the way most forms of psychosocial care have been conceptualised (Chesler, 1993). Certainly, people with cancer experience distress, and certain interventions may alleviate such distress, but is it necessary to term such distress 'psychological', thus enveloping it with an air of 'pathology?' Similarly, is it necessary to institute highly professionalised 'psychological' interventions, further amplifying this pathological mood? Perhaps the person with cancer is just that, a person like you or me, dealing with a major life crisis, which involves not just the victim, but also his or her family, friends, and arguably, even his or her broader community.

Such is the debate on the academic side of the fence. The victim's perspective, however, is unknown. Do people with cancer understand themselves as suffering from 'psychological distress', thus needing 'psychological intervention', or do they understand themselves to be socially marginalised people, requiring political advocacy and empowerment? Perhaps neither, because ultimately such is academic talk. A review of the utilisation trends of psychosocial care, and a subsequent survey of such trends here in the Cape (chapter 3) suggested, however, that people with cancer do have some opinions, because why else would they resist the more professionalised versions of psychosocial care, and tentatively embrace the less professionalised versions?

Chapter 4 set the stage for an alternative attempt at understanding the person with cancer. Instead of measuring attitudes, personality traits, or levels of 'psychological distress', it was argued that we could more usefully understand the person with cancer as a novelist-historian; a narrator of his or her life-experience, in turn informing the 'reality' of this life-experience (Hermans & Kempen, 1994). According to this approach, people make sense of themselves and their worlds using the categories inherent in language and discourse. Particularly in this modern world, however, we are confronted with contrast, difference, and dilemma (Billig et al., 1988). We are faced with multiple ways of making sense of ourselves, ways which may quite frequently conflict. In this sense we are not just one-dimensional narrators, but we are also arguers and debaters. We continuously argue with others and with ourselves, attempting to bring some coherence and sense to this chaotic, spiralling mess we call consciousness.

According to some authors (e.g. Frosh, 1991) the current (post-modern) fragmentation of self and culture is not an easy load to endure. We are, in many ways, becoming 'narcissistic': craving for emotional satisfaction, we continuously evaluate our 'selves' as they appear to others, becoming obsessed with roles. In response to this 'crisis of the self' - this tension - we try to construct a stable self which makes sense of and integrates the various forces impinging on us - forces which, because of their fragmenting and contrasting nature, always seem to have the power to tear us apart (Frosh, 1991). Under ordinary circumstances, however, most of us appear to deal with the fragmentary reality in a relatively adaptive manner. Either we celebrate our post-modern diversity, and take joy in difference and change (Deleuze & Guattari, 1972; Fox, 1990), or we somehow construct a stable sense of self and meaning. And yes, most of us do suffer from a certain emptiness and emotional depletion, but it is bearable and certainly no worse than the way things could be, either in the past or in poverty stricken areas - violence, poverty, etc.

The person with cancer presents a distinct case, however. When diagnosed with cancer, the bounds of one's meaning structure are tested to their limits (Moss, 1992). A diagnosis cuts across stable patterns, instantly destroying previous life goals and expectations. The person needs to 'digest' these changes, and then commence with a careful reconstruction of the shattered self, somehow creating some sense of order and meaning. One could argue that the threat of death adds a distinctive dimension to the narrative process, emphasising the 'meaningfulness' of life and the after-life. Such meaningful narratives are not dreamt up from the depths of mind, however, but external discursive resources are accessed, via a continuous process of discussion with self and others; reading, observing, generally engaging with the world. From a discursive or narrative position, such, it appears, is the 'coping process.'

The person with cancer, in this regard, constructs his or her experience using discourses which have something to say about life with cancer; discourses which perhaps most importantly, inform the sufferer how to go about dealing with the situation. He or she could access 'tried and tested' religious discourses, or even listen to the advice of an uncle with cancer and be inspired by a television documentary portraying life with cancer. Most notably for our purposes, however, the person with cancer also has access to a system of psychosocial care; a system dedicated to helping people with cancer cope with their situation. Counselling and psychotherapy is offered to ease depression, support groups provide social support, and an 'I Can Cope' course is offered to help people with cancer 'cope.' He or she is exposed to posters, pamphlets, radio and television advertisements, and general everyday talk, all of which, it can be assumed, paint a picture of what this system of psychosocial care is about. Such information is either new for the person with cancer, or slots into previous knowledge and understanding of psychosocial matters more generally. Either way, the person with cancer has available to him or her, psychosocial discourses which have a significant amount to say about life with cancer and how to go about dealing with it. The end result, however, is a rejection of most professionalised forms of psychosocial care.

In order to 'return to the subject', to understand how the person with cancer has made sense of his or her life and situation, *and* how he or she has made sense of the system of psychosocial care, a discourse analysis of several focus groups and interviews with people with cancer was performed in chapter 5. This final part of the study depicted how people with cancer rhetorically juggled an individualistic discourse with a psychological discourse, resulting in the domination of the rational 'I'. Professionalised psychosocial services were rejected, in this regard, because they threatened the existence of the rational, self-contained, and self-aware 'I'. The idea that a professional expert could have something to say about the 'psychological' operations of 'my mind' is difficult to deal with, because 'I', as a rational, self-aware being, am that very 'mind'. *My* fighting spirit, *my* courage, *my* positive attitudes are not 'psychic defences', they are part and parcel of the meaning system keeping me alive at all. 'Authentic' relationships are thus required, either with family, friends, a church community, or fellow patients. Such relationships are 'natural', 'real', 'authentic', 'not artificial', and above all, they do not threaten the reality and meaningfulness of *my* experience as a hero-victim.

Both discourses have been extensively described in chapter 5, as have the rhetorical strategies used to ensure domination of the rational 'I'. Unexamined, however, is psychosocial oncology's relationship with these discourses. Certainly, both discourses flow through popular culture, but what has psychosocial oncology, as a science and practice, to say about them? How does the discipline of psychosocial oncology and its associated system of psychosocial care 'recycle' (Parker, 1991) the present discourses back into culture, and ultimately back into the lives of people with cancer? These issues will be briefly discussed in the following two sections.

2. PSYCHOLOGICAL DISCOURSES AND PSYCHOSOCIAL ONCOLOGY

As discussed earlier, people with cancer are presented with a system of psychosocial care, expressing itself as various types of intervention, media advertising, pamphlets, 'psychological' literature, CANSA offices, etc. etc. The discourse analysis showed that psychosocial care, and in particular the more professionalised services, were understood in terms of a psychological discourse infused with psychodynamic principles. Respondents would talk about needing "some clarification", wanting "my emotions explained", and understanding "reactions that I hadn't worked through." Psychodynamic theory certainly has infused popular culture (Parker, 1991), and it is thus not surprising that lay people categorise all types of 'psycho-' services and professionals in the psychodynamic camp. In discursive terms, psychosocial care for cancer patients is understood in psychodynamic terms because this is the only terminology people have available to them to describe 'psycho-' matters.

Within such psychodynamic terminology, we are all, to varying degrees, 'traumatised' (or neurotic) individuals. The relative peace of rationality and sanity, according to this model, is very often just a facade covering a chaotic cauldron of fantasies and pent-up emotional energy. Consciousness, in other words, is just the tip of the ice-berg of who we are, with the result that the rational agent in firm control over his or her thoughts and feelings becomes no more than a mythological illusion. Who we are, and why we behave in particular ways, cannot be fully understood by our own naive perspectives, predominantly because our cognitions and perspectives are secondary to - and partly determined by - our inner world of emotional dynamics.

Rose (1990), drawing on the work of Michel Foucault, has attempted to describe how the institution of psychology 'makes' individuals with such inner worlds. In the first place, subjectivity needs to enter the visibility of experts. A 'regime of visibility' is established which objectifies the observed within a common plane of sight (Wilbraham, 1994, drawing on Rose and Foucault). Psychotherapeutic practices (e.g. free association, analysis of dreams, personality tests, psychological research - this study!), in this regard, operate as confessional techniques which make visible certain 'traces' of the hidden self. A depression rating scale or a clinical interview thus asks the patient to think and speak about an emotional life they may not have thought or known about previously. Secondly, institutionalised theoretical bodies are used to classify and order such 'traces' of the hidden self in terms of conformity and deviation from norms (e.g. when does anxiety become 'neurotic', when does 'feeling down' become Major Depression). Such bodies of knowledge position individuals in dependent relationships to experts, since it is the expert (the therapist) who diagnoses, advises, educates, interprets, motivates, and possibly cures. The patient, on the other hand, is attracted to the 'normal' and 'healthy' images of self (e.g. the integrated self), and is told to seek professional help when made anxious by apparent deviations from such norms.

Of primary importance, however, is the construction of an intriguing 'deep' 'inner' world of which the owner has little awareness or understanding. Wilbraham (1994), for example, illustrated how advice columnists psychologise various problems (e.g. 'attractiveness'), by setting up binary positions between the 'inside' (i.e. a deep inner core, a psyche, 'the real self') and the 'outside' (surface, body-shell, facade). Various rhetorical strategies then prioritised the 'inside', (e.g. 'working through' unresolved or unconscious emotions), and marginalized the naive outer 'surface' or facade. Such prioritisation of the 'inner' was partly accomplished by associating it with a hierarchy of professional status and expertise. Only clinical psychologists (as opposed to counsellors), for example, appeared to have the skill to deal with 'deep, underlying psychological problems.' Only such experts could help the applicant 'uncover' and 'clarify' hidden conflicts and motives. Respondents in this study appeared to fall prey to similar associations. When confronted with the idea of seeing a psychologist, many respondents would talk about the 'clarification' of 'deep' emotional issues.

The psychologised individual, therefore, is faced with an incredibly complex and out-of-awareness self. Ironically, however, the ideal (successful) psychologized individual is the integrated individual; a self-knower who is at least partly in control over the 'complex' aspects of the self. Therapy, in this regard, aims to bring into awareness what was repressed, and thus strengthen the rational and realistic ego. In light of our broader metatheoretical stance, some problems are thus immediately apparent. For one, the approach makes the implicit assumption that such a 'deep', 'real', and perhaps even unified (or coherent) self exists, and secondly, some commentators have questioned the assumption that the self-knower is actually better off in terms of psychological well-being (Wicklund & Eckert, 1992).

Be that as it may, the psychologized individual is expected to embark on a thorough process of self-reflection and self-consciousness, i.e. he or she needs to 'cultivate' the self (Rose, 1990, p.197). Parker (1992), in this regard, has noted how psychodynamic theory has woven itself through Western culture with two implications. Firstly, it offers a vocabulary to lay people which allows them to explore and reflect upon emotions and relationships, keeping in mind the broader aim of self-revelation and self-fulfilment. Secondly, however, "it operates as a way of talking about repression and the unconscious which draws the speaker into the peculiarly vicious spiral of confessional reflexivity" (p.104). The 'real' self, in this regard, remains eternally elusive since the expert and his or her realm of expertise, claim hegemony over aspects of the self which the client cannot know or understand without help (the 'deeper' side).

To conclude, the psychodynamic discourse presents us with a dilemmatic state of affairs. On the one hand, we are asked to recognise a deeper and more complex side to ourselves; an 'inner world' of infantile fantasies, tensions, and emotions. We are told that the dynamics in this inner, but unconscious world, to a large extent determine who we are, and what we think, say, and do. On the other hand, however, we are presented with an ideal, integrated self; the self-knower. In order to attain this state we need to 'think' about our emotions (Emanuel, 1992), bringing into consciousness what was unconscious, and 'working through' unresolved infantile tensions and conflicts. We are told to express our emotions and to grieve over our multitude of losses (Barraclough, 1992). Only through such 'insight', or confessions, are we able to make progress toward integration. In light of the 'depth' of the unconscious and its ego-protective defences, however, we are hardly expected to make progress on our own. On the contrary, the very idea of an unconscious entails a body of expertise and experts of it, and as such we are asked to consult such experts for the necessary ego support, interpretations, and psychotherapeutic frame. The discourse analysis furthermore illustrated, however, that the relationship also runs the other way. The very notion of a psychological expert carries with it the implication that a part of the self or 'mind' is open to expert examination, and thus closed to lay (me) examination. In other words, all of the psychosocial services that depend to some extent on the participation of a psychological professional, carried with them certain basic psychodynamic implications.

In the survey it became apparent that people with cancer seem to have a particular strong aversion to exactly these more professionalised forms of psychosocial care. The discourse analysis, in turn, showed how this resistance revolved around the survival of the rational 'I'. Instead of expressing emotions, and succumbing to the 'expertise' of psychological professionals who could 'clarify' and help 'work through' one's emotional problems, respondents expressed fighting spirit, positive thoughts, and a faith in their ability to 'keep the mind right'. The psychological discourse, in other words, clashed with a dominating individualistic discourse which prized the virtues of rationality and moral strength.

3. INDIVIDUALISM AND PSYCHOSOCIAL ONCOLOGY

Individualism and the ideological imperatives of maintaining hope and good morale are easily recognisable in the popular culture surrounding cancer. Saillant (1989), in this regard, identified and elucidated a new discourse on cancer; one centred on survival rather than death. This discourse, which Saillant feels is embodied in the north American cancer education campaign slogan; 'we can beat cancer' (and here in South Africa, CANSA's 'Cancer can be Beaten' campaign), resulted in a new category of patient: the hero-victim. Survival, in this sense, is strongly associated with values such as fighting attitude, courage, and positive attitudes. The following quotes in a recent CANSA publication serve to illustrate the presence of the individualistic discourse in popular cancer media.

"Shining example of hope and courage." (Hope in Action, 1995, p.1)

"...is a shining example of a brave little boy who has never once expressed any bitterness about his disease." (Hope in Action, 1995, p. 1)

Such themes clearly infuse Western culture and are images most of us strive toward in daily life. And as shown in the discourse analysis, people with cancer in particular appear to feel the need to emulate these inspired images of mental strength, courage and dignity.

Psychosocial professionals could argue, however, that such values are destructive macho attitudes preventing the integration of a real and honest self. The hope could be expressed that once people become honest with themselves, and look inward, they will start seeking out professional help. Individualism, in other words, is 'culture' and psychodynamics is 'reality.' The conceptual difference between cultural values and scientific facts collapses, however, when we examine the way 'science' recycles 'culture', and 'culture' recycles 'science' (Sampson, 1985, 1993). It has been argued, in this regard, that psychodynamic theory is neither 'science' nor 'culture', but is a particular discourse which constructs 'deep' inner realities (Rose, 1990). Professional and academic practices prove the 'truth' of psychodynamic realities, but it is 'culture' (language and discourse) which make such 'truth' possible at all. Only those who have the terminology of psychodynamic theory are able to perceive any of its phenomenon. Psychodynamic theory is thus very evidently 'true', but only as far as social beings speak its language and practice according to its implicit rules. The point to be made here is that the same applies to the individualistic discourse.

Psychological professionals may complain of people's 'coping facades', their 'masking' of feelings and symptoms, and their generally abrasive macho attitudes. Professionals may hope to see such 'unadaptive' and 'destructive' attitudes go, to be replaced by a more honest appraisal of the self. Lest we forget, however, individualism is not merely 'culture', but is also 'science'. In contradiction to the psychodynamic discourse, the *virtues* of fighting spirit, positive attitudes, personal control, and even positive 'illusions', have all been 'scientifically' proven. The reader is referred to three areas of literature in this regard:

1. Lazarus & Folkman's Transactional model of Stress and the Ways of Coping scale (Bombardier, et al., 1990; Dunkel-Schetter et al., 1992; Folkman & Lazarus, 1988; Jensen & Karoly, 1991; Revenson & Felton, 1989; Schussler, 1992; Stanton & Snider, 1993).
2. Shelley Taylor's Cognitive Adaptation theory (Denne & Thompson, 1991; Felton & Revenson, 1984; Sappington, Bryant, & Cohen, 1990; Taylor, 1982, 1983; Taylor & Brown, 1988; Taylor, Buunk, & Aspinwall, 1990; Taylor & Lobel, 1989; Thompson, 1981; Thompson, Sobolew-Shubin, Galbraith, Schankovski, & Cruzen, 1993; Thompson & Spacapan, 1991; Watson, Greer, Pruyn, & Van den Borne, 1990; Zika & Chamberlain, 1992).
3. Watson & Greer's Coping Styles approach and the Mental Adjustment to Cancer scale (Burgess et al., 1988; Greer et al., 1979; Greer, Moorey & Watson, 1989; Greer & Watson, 1987; Pettingale et al., 1985; Watson et al., 1984; Watson, Greer, Young, Inayat, Burgess, & Robertson, 1988).

Coping, according to this body of literature refers to what the individual brings to a stressful situation in terms of attitudes, thoughts, feelings, and behaviour, which more often than not are aimed at reducing the perceived threat and resulting negative feelings. These three theoretical models of coping are thus all, loosely defined, cognitive approaches, since they place predominant emphasis on people's perceptions, thoughts, attitudes, appraisals, and beliefs, i.e. their subjective appraisal of reality. Their research conclusions can be loosely summarised by the assertion that 'good copers' are people who manage to maintain a positive attitude towards their situation and themselves. Problems occur, according to the cognitive approach, when beliefs become overly pessimistic and rigid (Moorey, 1994), culminating in a type of 'bad coping' pattern (e.g. wishful thinking, avoidance, self-blame).

At heart of all three theories lies the further assertion that people *actively* respond to their situation. People are not passively impacted upon by a cancer diagnosis, but respond to such an event in particular ways, with particular consequences to the ultimate degree of psychological adaptation. Taylor's (1983) model in particular, describes how people actively attempt to manage their thoughts and feelings, striving for coherence, personal control, and self-esteem. In light of the disabling and disempowering reality of a cancer diagnosis, it is thus striking to note that most people with cancer adapt remarkably well, and do this without seeking professional help (they use their social networks and individual resources) (Taylor, 1983).

In the world described by the coping literature, therefore, people are *active*, and at least to some extent, *rational thinkers*. We are not passive organisms, reacting in a stimulus-response pattern to our environment, but are at least to some degree rational agents, capable of managing (or guiding) our perceptions and thoughts, toward particular (more adaptive) directions. A cancer diagnosis, like any other threatening event, therefore presents us with a task. We can either remain rigid and pessimistic, or we can actively search for something positive - something that will either change the problem (e.g. seeking information, alternative treatments), or change our reaction to it (comparing ourselves to others who are worse off). We need to continuously assess and re-asses our situation, and are expected to develop appropriate cognitive strategies aimed at making sense of the situation. Ultimately, therefore, coping with cancer is a task only the individual with cancer can do. Interventions can help or guide the person toward more effective coping strategies, but it is always still the victim who is required to do the coping.

The coping literature, therefore, has presented us with a technical interpretation of the individualistic discourse identified in the discourse analysis. The coper found in the coping literature, and in our discourse analysis, personifies the Western individualist: a rational being in control of his or her thoughts and behaviour, and thus indirectly in control of his or her emotions. Emotions may 'well up' but they can be controlled with some effort, and more importantly *should* be controlled in many instances. Keeping the 'spirits up', maintaining 'morale', or more technically speaking; instilling 'positive illusions' and 'positive attitudes' are the types of strategies respondents in this study claimed to have used. They are also, however, the types of strategies people have used for centuries in dealing with adversity. Such themes are still the essence of Western culture, and the coping literature thus predictably reflects these tenets.

The coping literature not only mirrors cultural 'reality', however, but indirectly recycles it back into popular culture (see Sampson, 1993, 1995). Pop-psychology books and other lay literature draw on the values in popular culture, *and* on the scientific 'evidence' available which appears to legitimate such values. People with cancer may thus read Victor Frankl's (1959) eloquent assertions regarding the search for meaning in suffering, and find that such theory 'rings true'. Similarly, a patient may encounter a self-help book written by an eminent 'M.D.' expounding the virtues of a fighting spirit, thus affirming what this patient has always believed morally. Ironically, however, even the very names of psychosocial interventions can affirm the individualistic discourse. On being confronted with advertising for the 'I can Cope' course, people with cancer in this study responded by asserting their success as 'copers', arguing that *yes, they can cope* since they keep their mind 'right' and 'positive'. But would they actually attend a coping course? Of course not since such expert intervention threatens the very idea that they would be capable of 'keeping their mind right'. It implies that they may not be coping so well, *and* that they may not know why they are not coping so well. In come the psychological discourses, with the assertion that one's rational 'I' may just be a naive delusion.

4. CANCER AND THE INDIVIDUALISTIC IMPERATIVE

This study has illustrated how the person with cancer is able to make sense of him- or herself in two rather contrasting manners; one necessary and one, because of the other, impossible. The necessity of the individualistic discourse could be questioned, however, since if it is 'just' a discourse then why could it not be transformed or resisted, and what about alternatives? Certainly, people could obviously make sense of their lives in different manners, even in ways which could allow an incorporation of psychological discourses.

The individualistic discourse embodies a theme, however, which could be regarded as imperative to the person facing a life-threatening illness. As the body degenerates and threatens to stop functioning all together, so the sufferer may begin to wonder what is left of who he or she is. The illness may progress, perhaps to the stage where the sufferer is barely able to recognise him- or herself in the mirror. Even at this stage, however, there will still be a relatively rational, self-aware 'I' gazing upon him- or herself. It is this ability to think, and most importantly, to imagine a situation that is different, which affirms a sense of being alive. Fox (1990), drawing on the work of Deleuze & Guattari (1972), describes this elusive ingredient to being as 'Desire': a libidinal force which enables and 'de-territorializes' the body inscribed (and fixed) in discourse, allowing it to be other than it is, and thereby *resist*. One can compare it to Nietzsche's passionate will-to-power, Robert Pirsig's (1972, 1992) sense of Dynamic Quality, the Taoist Qi, or more simply, that which makes us, as *agents and persons*, feel alive.

Under ordinary circumstances people may allow a receding of the rational 'I'. We can play with the idea of our unknown self and unconscious, and also play with the idea of consulting a therapist, knowing, however, that we are still very much alive as persons. When confronted with a chronic life threatening illness, however, the task to hang on to one's sense of Desire may be desperate. As one's body stops co-operating so the individualistic discourse offers the possibility of maintaining a fighting spirit (mentally and spiritually) and a sense of 'dignity' (again mentally or spiritually). By maintaining the rational 'I' and one's faith in one's own ability to reason and control emotion, so one's sense of 'being' remains intact.

According to Fox (1990), there would certainly still be room for 'caring', but in a slightly different sense to the expert-patient sense we have become accustomed to. Fox, in this regard, drew on the work of Cixious to describe the 'Gift' relationship. Such are open-ended, trusting relations of generosity, in which one person invests another with the gift of his or her desire. In this way the sufferer is not inscribed by a host of professionalized discourses (e.g. medical, psychodynamic, etc.) but is supported in his or her attempts at 'becoming other.' The cared-for is invested with the power to 'become.'

5. SUGGESTIONS FOR FUTURE RESEARCH: PARTICIPATORY ACTION RESEARCH

This study has taken a critical stance to mainstream positivist research methods in psychosocial oncology. The primary focus, in this regard, has been on the inability of this approach to develop cost-effective interventions, which both address relevant problems and are acceptable to consumers. Psychosocial oncology and its associated system of psychosocial care are unavoidably so political activities. Its metatheoretical and professional roots have ensured, in this regard, that psychosocial problems and interventions are conceptualised in terms that are unfamiliar or threatening to the person with cancer. Due to this academic and professional hegemony, hundreds of studies are published and numerous conferences are organised throughout the world, which ultimately have little influence on the life of the person with cancer. Attending such a conference, and listening to numerous papers on psychosocial issues and interventions, I was struck by the conspicuous absence of our very own subject matter: the person with cancer him or herself. If this conference was really about the person with cancer, and his or her welfare, then where was this person? Where were the patient representatives lobbying for their needs (needs conceptualised by patients themselves)?

Participatory action research (Chesler, 1993; Norman & Brandeis, 1992) has, in recent years, been proposed as a constructive response to the above discussed dilemmas. This research approach not only seeks to generate new knowledge, but actively attempts to solve problems and empower the so-called victims. The primary task of this approach is to enrol the participation of one's subjects (people with cancer) as co-researchers. The research team can then proceed through a cyclical process of fact-finding, planning, action, and evaluation. Instead of avoiding influence and effect on one's subject matter (objectivity), in action research such effect is a primary goal. The research process itself must be on-going problem-solving. As a result there is no distinction between research and intervention; the research itself becomes an on-going, problem-solving, self-evaluatory intervention.

It is argued by proponents of this approach, that the active participation of key participants in the research process increases the likelihood that interventions will reflect the needs, interests, and values of survivors as well as those of health and social service professionals (Chesler, 1993; Norman & Brandeis, 1992). Such an approach is furthermore most consistent with the themes elicited in this research: aprofessional leadership and respect for experience-based knowledge (Chesler, 1993). For detailed guidelines on the setting up of action research, the reader is referred to Chesler (1993) and Norman & Brandeis (1992).

6. PSYCHOSOCIAL CARE FOR PEOPLE WITH CANCER: RECOMMENDATIONS

The presentation of an ideal system of psychosocial care, based on the present empirical findings and theoretical conclusions, will serve as the recommendations for improvements in psychosocial care. It must be emphasised that the following suggestions cannot be treated as more than that, since an 'ideal' system would be dynamic, patient-driven, context-driven, and problem focused (Chesler, 1993). Nevertheless, the present result do indicate certain suggestions. The ideal system, it is envisaged, would consist of two levels of care, based on a closer partnership between professional and consumer (patient) (Brennan & Sheard, 1994; Jacobs & Goodman, 1989).

Firstly, a non-professionalised consumer-friendly system would attempt to establish contact with as many patients as possible. This level of intervention would, as far as possible, be patient run and managed. Newly diagnosed patients would be offered a visit by a veteran patient trained in basic counselling skills. Pamphlets and newsletters would also keep patients informed about accessible 'self-help groups', 'informal gatherings', and 'seminars.' This system would aim to provide patients with additional support, focusing primarily on the provision of information, the sharing of experiences, and 'moral support.'

The prevention of psychosocial problems would be an additional function of this level of care, since active coping and continuous engagement with the world would be encouraged. Problems can be dealt with before they manifest as 'clinical depression' or other pathology. The problem, furthermore, would be conceptualised in terms familiar to patients themselves, as will the 'intervention.' The emphasis here is on keeping matters as grass-roots and common-sensical as possible. At this level of care, respect for the authenticity of the patient's experience is vital. The regular input from professional 'consultants' would ensure that staff are adequately trained and supervised. Lastly, this level of care would serve as a screening system for serious psychological morbidity. By maintaining contact with as many patients as possible, the chances of detecting psychological morbidity should improve significantly. At this point a system of referral would come into operation, whereby the patient is 'referred on' to an appropriate professional.

At this second level of care, psychiatrists and psychologists would deal with serious psychological morbidity. Social workers and counsellors would provide more practically orientated support and advice.

An organisation like CANSA, in conjunction with hospital services, could provide the infrastructure for such a system of care. The primary level of care, could in this regard be supported through relevant organising, the provision of sponsorship, and the making available of professional 'consultants'. The emphasis would, in this regard, be on patient empowerment: providing the training and infrastructure to make such a system of care possible.

The promotion of this proposed system of care is of vital importance for its success. A close working relationship with hospital services should ensure that *personal* contact is made possible between newly diagnosed patients and members of the system of care. Regular pamphlets and *personal* invitations to join meetings are important in this regard. Professionalized talk or a patronising approach should be avoided.

The exact form of this ideal system of care cannot be determined at this point. In fact, this attempt so far has already contradicted the spirit of this study's conclusions. An ideal system of care would not be an academically derived and universally applicable structure, but a dynamic, patient driven and problem-focused system of care.

6. CONCLUSION

Utilising theoretical discussion and empirical study, this thesis has argued that the professional's response to cancer associated concerns is not necessarily correct, appropriate, or neutral. On the contrary, the professional's response forms part of a broader psychologised 'culture', which constructs the concerns of people with cancer (and their remedies) in very particular ways. Professional care is resisted in this regard, by people with cancer who make sense of their lives using a different and contrasting individualistic 'culture', one which prizes the virtues of fighting spirit, and personal and rational control over self. Before a collaborative partnership between psychosocial professionals and people with cancer can develop, the professional must acknowledge the user's legitimate and irreducible attempts at maintaining a sense of self.

"He must come down to my level."

\- a patient

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✓

APPENDIX A:

Since the diagnosis of your illness, have you ever:

1. *Consulted with a psychiatrist?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

2. *Undergone individual counselling or psychotherapy with a counsellor or psychologist?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

3. *Consulted the department social worker?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

4. *Participated in a Coping Skills course?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

5. *Participated in a support group led by professionals (social worker, counsellor, psychologist)?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

6. *Participated in a support group led by patients or ex-patients?*
Yes ( ) No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

7. *Attended an informal or social gathering for patients, ex-patients, and their family members?* Yes ( )No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

8. *When you were first diagnosed, were you given the opportunity to talk to an ex-cancer patient or long-term survivor concerning the illness and treatment or any other problems you might have encountered?*
Yes ( ) No ( )

If such an opportunity was given did you speak to such a person?
Yes ( ) No ( )
If "yes", did you find it helpful? Not at all ( ) Somewhat ( ) Very Much So ( )

Since the diagnosis of your illness have you ever wanted to, or do you currently feel you would like to:

1. *Consult with a psychiatrist?* Not at all ( ) Somewhat ( ) Very Much So ( )
2. *Undergo individual counselling or psychotherapy with a counsellor or psychologist?* Not at all ( ) Somewhat ( ) Very Much So ( )
3. *Consult the department social worker?* Not at all ( ) Somewhat ( ) Very Much So ( )
4. *Participate in a Coping Skills course?* Not at all ( ) Somewhat ( ) Very Much So ( )
5. *Participate in a support group led by professionals (social worker, counsellor, psychologist)?* Not at all ( ) Somewhat ( ) Very Much So ( )
6. *Participate in a support group led by patients or ex-patients?* Not at all ( ) Somewhat ( ) Very Much So ( )
7. *Attend an informal or social gathering for patients, ex-patients, and their family members?* Not at all ( ) Somewhat ( ) Very Much So ( )
8. *When you were first diagnosed, would you have liked to have been given the opportunity to talk to an ex-cancer patient or long-term survivor concerning the illness and treatment or any other problems you might have encountered?* Not at all ( ) Somewhat ( ) Very Much So ( )

If you ever wanted to use any of the above services, but did not do so, what prevented you from you using them?

....

....

....

From the time you were first diagnosed with cancer, you have probably received help and support from a variety of people and organisations (eg. your doctor, the nurses, your spouse, your family, your friends, people at the South African Cancer Association, the church, support groups, a traditional healer.) Could you tell me who, in your opinion, has been the most important helper or support for you, in dealing with the problems you have encountered? (Mention several people or organisations if you wish)

....

....

Could you tell me who, in your opinion, has best undestood the types of problems you have encountered?

....

....

Do you feel your friends have been helpful in dealing with your problems?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel your friends have understood the problems you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel your doctor has been helpful in dealing with your problems?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel your doctor has understood the problems you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel your family has been helpful in dealing with your problems?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel your family has understood the problems you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

....\...............................

Do you feel fellow patients can possibly understand the problems and concerns you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel fellow patients could possibly have helped or supported you in dealing with the problems you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel you could possibly be of any help or support to other people with cancer?

Not at all ( ) Somewhat ( ) Very much so ( )

Why do you think fellow patient can, or cannot help and support each other?

....

....

Do you feel fellow patients can possibly understand the problems and concerns you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel fellow patients could possibly have helped or supported you in dealing with the problems you have encountered?

Not at all ( ) Somewhat ( ) Very much so ( )

Do you feel you could possibly be of any help or support to other people with cancer?

Not at all ( ) Somewhat ( ) Very much so ( )

Why do you think fellow patient can, or cannot help and support each other?

....

....

APPENDIX B:

Table 8: Chi-square values for respondents expressing no interest versus some interest in psychiatry, on "race", marital status, earning status, and time since diagnosis.

Variables	No interest O(E)	Some interest O(E)	chi sq. value	df	significant
N	70	14			
% of total sample	83.30%	16.70%			
Demographics					
'Race'					
White	32 (32.9)	7 (6.5)	0.125	1	NS*
Coloured	39 (38.9)	7 (7.7)			
Marital Status					
Married	49 (49.2)	10 (9.8)	0.011	1	NS*
Single/D/W	21 (20.8)	4 (4.2)			
Earning status					
1	37 (35)	5 (7)	1.371	1	NS*
2	33 (35)	9 (7)			
Cancer stage					
1	14 (15.8)	5 (3.2)	3.204	3	NS**
2	32 (29.2)	3 (5.8)			
3	11 (11.7)	3 (2.3)			
4	13 (13.3)	3 (2.7)			
Treatment stage					
Radical	8 (9.2)	3 (1.8)	2.604	2	NS***
Palliative	21 (22.5)	6 (4.5)			
Remission	41 (38.3)	5 (7.7)			

* **critical value at $p<0.05$= 3.84**

** **critical value at $p<0.05$= 7.82**

*** **critical value at $p<0.05$= 5.99**

Table 9: Means and two-sample t-test p values for respondents expressing no interest versus some interest in psychiatry, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		**No interest**	**Some interest**	**t value**	**df**	***p***
	N	70	14			
	% of total sample	83.30%	16.70%			
Demographics						
	Age	55.41	47.86	1.882	16	0.078
Psychological distress						
	HADS:Depr	3.11	5.21	2.122	17	0.049 S
	HADS:Anx	5.96	9.29	2.682	19	0.015 S
	BDI	6.40	12.36	2.051	15	0.058
Support						
	Family	5.39	5.21	0.559	18	0.583
	Friends	5.09	5.00	0.264	18	0.794
	Doctor	5.74	5.07	2.114	15	0.049 S
Attitudes toward fellow patient support						
	Understand	2.70	2.86	1.363	25	0.185
	Support	2.51	2.50	0.066	17	0.948
	Other	2.67	2.79	0.877	22	0.389

Table 10: Chi-square values for respondents expressing no interest versus some interest in psychotherapy and counselling, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest O(E)	Some interest O(E)	chi sq. value	df	significant
	N	69	15			
	% of total sample	82.14%	17.86%			
"race"						
	white	29 (32.0)	10 (7.0)	3.007	1	NS*
	coloured	40 (36.9)	5 (8.0)			
Marital Status						
	Married	47 (48.5)	12 (10.5)	0.832	1	NS*
	Single/D/W	22 (20.5)	3 (4.5)			
Earning status						
	1	39 (34.5)	3 (7.5)	6.57	1	S*
	2	30 (34.5)	12 (7.5)			
Cancer stage						
	1	15 (15.6)	4 (3.4)	1.346	3	NS**
	2	28 (28.8)	7 (6.3)			
	3	13 (11.5)	1 (2.5)			
	4	13 (13.1)	3 (2.9)			
Treatment stage						
	Radical	9 (9.0)	2 (2.0)	0.263	2	NS***
	Palliative	23 (22.2)	4 (4.8)			
	Remission	37 (37.8)	9 (8.2)			

***	critical value at $p<0.05$= 3.84**
****	critical value at $p<0.05$= 7.82**
*****	critical value at $p<0.05$= 5.99**

Table 11: Means and two-sample t-test p values for respondents expressing no interest versus some interest in psychotherapy and counselling, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables		No interest	Some interest	t value	df	*p*
	N	69	15			
	% of total sample	82.14%	17.86%			
Demographics						
	Age	55.39	48.47	2.190	21	0.039 S
Psychological distress						
	HADS:Depr	3.13	5.00	1.847	18	0.081
	HADS:Anx	5.86	9.53	3.137	21	0.005 S
	BDI	6.80	10.13	1.479	19	0.155
Support						
	Family	5.36	5.33	0.103	22	0.919
	Friends	5.04	4.87	0.744	20	0.465
	Doctor	5.74	5.13	2.021	16	0.060
Attitudes toward fellow patient support						
	Understand	2.68	2.93	2.737	44	0.009 S
	Support	2.49	2.60	0.587	22	0.563
	Other	2.68	2.73	0.389	23	0.701

Table 12: Means and two-sample t-test p values for respondents expressing no interest versus some interest in social work, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	58	26			
% of total sample	69.05%	30.95%			
Demographics					
Age	55.95	50.15	2.481	69	0.015 S
Psychological distress					
HADS:Depr	3.17	4.12	1.123	38	0.268
HADS:Anx	6.00	7.65	1.461	41	0.152
BDI	6.16	10.15	2.052	37	0.047 S
Support					
Family	5.41	5.23	0.685	39	0.498
Friends	5.19	4.73	0.576	37	0.124
Doctor	5.66	5.58	0.407	41	0.686
Attitudes toward fellow patient support					
Understand	2.66	2.88	2.385	75	0.020 S
Support	2.45	2.65	1.350	52	0.183
Other	2.66	2.77	1.030	61	0.307

Table 13: Chi-square values for respondents expressing no interest versus some interest in social work, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	significant
	N	58	26			
	% of total sample	69.05%	30.95%			
"race"						
	white	31(26.9)	8(12.1)	3.710	1	NS*
	coloured	27(31.1)	18(13.9)			
Marital Status						
	Married	41 (40.7)	18 (18.3)	0.018	1	NS*
	Single/D/W	17 (17.3)	8 (7.7)			
Earning status						
	1	26 (29)	16 (13)	2.005	1	NS*
	2	32 (29)	10 (13)			
Cancer stage						
	1	12 (13.1)	7 (5.9)	2.645	3	NS**
	2	22 (24.2)	13 (10.8)			
	3	11 (9.7)	3 (4.3)			
	4	13 (11.0)	3 (5.0)			
Treatment stage						
	Radical	6 (7.6)	5 (3.4)	1.407	2	NS***
	Palliative	20 (18.6)	7 (8.4)			
	Remission	32 (31.8)	14 (14.2)			

*** critical value at $p<0.05$= 3.84**
**** critical value at $p<0.05$= 7.82**
***** critical value at $p<0.05$= 5.99**

Table 14: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a coping skills course, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	65	19			
% of total sample	77.38%	22.62%			
Demographics					
Age	55.98	47.89	2.957	33	0.006 S
Psychological distress					
HADS:Depr	3.09	4.74	1.713	24	0.100
HADS:Anx	5.80	8.95	3.086	34	0.004 S
BDI	6.80	9.42	1.417	31	0.167
Support					
Family	5.52	4.79	2.178	22	0.040 S
Friends	5.05	4.89	0.717	27	0.479
Doctor	5.69	5.42	1.148	24	0.262
Attitudes toward fellow patient support					
Understand	2.69	2.84	1.386	41	0.173
Support	2.49	2.58	0.484	28	0.632
Other	2.69	2.68	0.063	32	0.950

Table 15: Chi-square values for respondents expressing no interest versus some interest in a coping skills course, on "race", marital status, earning status, and time since diagnosis.

Variables		**No interest**	**Some interest**	**chi sq. value**	**df**	**significant**
	N	65	19			
	% of total sample	77.38%	22.62%			
"race"						
	white	30 (30.6)	9 (8.4)	0.118	1	NS*
	coloured	36 (35.4)	9 (9.6)			
Marital Status						
	Married	44(45.7)	15(13.3)	0.891	1	NS*
	Single/D/W	21 (19.3)	4 (5.7)			
Earning status						
	1	33 (32.5)	9 (9.5)	0.068	1	NS*
	2	32 (32.5)	10 (9.5)			
Cancer stage						
	1	13 (14.7)	6 (4.3)	1.565	3	NS**
	2	27 (27.1)	8 (7.9)			
	3	12 (10.8)	2 (3.2)			
	4	13 (12.4)	3 (3.6)			
Treatment stage						
	Radical	6 (8.5)	5 (2.5)	4.237	2	NS***
	Palliative	23 (20.9)	4 (6.1)			
	Remission	36 (35.6)	10 (10.4)			

* **critical value at $p<0.05$= 3.84**
** **critical value at $p<0.05$= 7.82**
*** **critical value at $p<0.05$= 5.99**

Table 16: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a professional support group, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	59	25			
% of total sample	70.24%	29.76%			
Demographics					
Age	56.58	49.04	3.164	65	0.002 S
Psychological distress					
HADS:Depr	2.95	4.56	1.997	40	0.053
HADS:Anx	5.72	8.19	2.371	49	0.022 S
BDI	6.46	9.37	1.633	47	0.109
Support					
Family	5.58	4.89	2.571	36	0.014 S
Friends	5.25	4.74	1.601	40	0.117
Doctor	5.72	5.44	1.380	38	0.176
Attitudes toward fellow patient support					
Understand	2.68	2.81	1.250	68	0.216
Support	2.47	2.59	0.821	62	0.415
Other	2.68	2.70	0.170	59	0.866

Table 16.1:Chi-square p values for respondents expressing no interest versus some interest in a professional support group, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	significant
	N	57	27			
	% of total sample	67.86%	32.14%			
"race"						
	white	29 (26.5)	10 (12.5)	1.411	1	NS*
	coloured	28 (30.5)	17 (14.5)			
Marital Status						
	Married	38 (39.4)	20 (18.6)	0.470	1	NS*
	Single/D/W	19 (17.6)	7 (8.4)			
Earning status						
	1	29 (28.5)	13 (13.5)	0.0546	1	NS*
	2	28 (28.5)	14 (13.5)			
Cancer stage						
	1	12 (12.9)	7 (6.1)	2.253	3	NS**
	2	24 (23.8)	11 (11.3)			
	3	8 (9.5)	6 (4.5)			
	4	13 (10.9)	3 (5.1)			
Treatment stage						
	Radical	7 (7.5)	4 (3.5)	0.715	2	NS***
	Palliative	20 (18.3)	7 (8.7)			
	Remission	30 (31.2)	16 (14.8)			

*** critical value at $p<0.05$= 3.84**
**** critical value at $p<0.05$= 7.82**
***** critical value at $p<0.05$= 5.99**

Tabel 17: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a self-help support group, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	49	35			
% of total sample	58.33%	41.67%			
Demographics					
Age	56.43	50.97	2.171	76	0.033 S
Psychological distress					
HADS:Depr	2.80	4.40	2.258	63	0.027 S
HADS:Anx	5.53	7.89	2.424	72	0.018 S
BDI	6.08	9.23	1.947	75	0.055
Support					
Family	5.59	5.03	2.409	56	0.019 S
Friends	5.16	4.97	0.677	64	0.501
Doctor	5.76	5.46	1.705	58	0.094
Attitudes toward fellow patient support					
Understand	2.69	2.77	0.729	81	0.468
Support	2.53	2.49	0.298	70	0.766
Other	2.69	2.69	0.073	79	0.942

Table 17.1: Chi-square p values for respondents expressing no interest versus some interest in a self-help support group, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	Significant
	N	49	35			
	% of total sample	58.33%	41.67%			
"race"						
	white	25 (22.8)	14 (16.3)	0.997	1	NS*
	coloured	24 (26.3)	21 (18.8)			
Marital Status						
	Married	34 (34.4)	25 (24.6)	0.041	1	NS*
	Single/D/W	15 (14.6)	10 (10.4)			
Earning status						
	1	25 (24.5)	17 (17.5)	0.049	1	NS*
	2	24 (24.5)	18 (17.5)			
Cancer stage						
	1	9 (11.1)	10 (7.9)	2.239	3	NS**
	2	23 (20.4)	12 (14.6)			
	3	7 (8.2)	7 (5.8)			
	4	10 (9.3)	6 (6.7)			
Treatment stage						
	Radical	6 (6.4)	5 (4.6)	0.077	2	NS***
	Palliative	16 (15.8)	11 (11.3)			
	Remission	27 (26.8)	19 (19.2)			

* **critical value at $p<0.05= 3.84$**
** **critical value at $p<0.05= 7.82$**
*** **critical value at $p<0.05= 5.99$**

Table 18: Means and two-sample t-test p values for respondents expressing no interest versus some interest in an informal gathering, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	47	37			
%	55.95%	44.05%			
Demographics					
Age	56.19	51.57	1.835	79	0.070
Psychological distress					
HADS:Depr	3.26	3.73	0.668	73	0.506
HADS:Anx	6.34	6.73	0.395	79	0.694
BDI	7.23	7.59	0.227	82	0.821
Support					
Family	5.57	5.08	2.127	57	0.038 S
Friends	5.00	5.19	0.692	76	0.491
Doctor	5.74	5.49	1.511	64	0.136
Attitudes toward fellow patient support					
Understand	2.64	2.84	1.934	80	0.057
Support	2.49	2.54	0.345	75	0.731
Other	2.70	2.68	0.237	81	0.813

Table 18.1: Chi-square p values for respondents expressing no interest versus some interest in an informal gathering, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	Significant
	N	47	37			
	%	55.95%	44.05%			
"race"						
	white	24 (21.8)	15 (17.2)	0.922	1	NS*
	coloured	23 (25.2)	22 (19.8)			
Marital Status						
	Married	33 (32.5)	25 (25.5)	0.068	1	NS*
	Single/D/W	14 (14.5)	12 (11.5)			
Earning status						
	1	24 (23.5)	18 (18.5)	0.048	1	NS*
	2	23 (23.5)	19 (18.5)			
Cancer stage						
	1	11 (10.6)	8 (8.4)	0.251	3	NS**
	2	20 (19.6)	15 (15.4)			
	3	7 (7.8)	7 (6.2)			
	4	9 (9.0)	7 (7.0)			
Treatment stage						
	Radical	7 (6.2)	4 (4.8)	1.071	2	NS***
	Palliative	13 (15.1)	14 (11.9)			
	Remission	27 (25.7)	19 (20.3)			

* **critical value at $p<0.05= 3.84$**

** **critical value at $p<0.05= 7.82$**

*** **critical value at $p<0.05= 5.99$**

Table 19: Chi-square p values for respondents expressing no interest versus some interest in a patient visit, on "race", marital status, earning status, and time since diagnosis.

Variables		No interest	Some interest	chi sq. value	df	Significant
	N	28	56			
	%	33.3%	66.7%			
"race"						
	white	12 (13)	27 (26)	0.215	1	NS*
	coloured	16 (15)	29 (30)			
Marital Status						
	Married	19 (19.7)	40 (39.3)	0.114	1	NS*
	Single/D/W	9 (8.3)	16 (16.7)			
Earning status						
	1	20 (14)	22 (28)	7.714	1	S*
	2	8 (14)	34 (28)			
Cancer stage						
	1	4 (6.3)	15 (12.7)	12.085	3	S**
	2	8 (11.7)	27 (23.3)			
	3	5 (4.7)	9 (9.5)			
	4	11 (5.3)	5 (10.7)			
Treatment stage						
	Radical	4 (3.7)	7 (7.3)	9.969	2	S***
	Palliative	15 (9)	12 (18)			
	Remission	9 (15.3)	37 (30.7)			

* **critical value at $p<0.05$= 3.84**

** **critical value at $p<0.05$= 7.82**

*** **critical value at $p<0.05$= 5.99**

Table 20: Means and two-sample t-test p values for respondents expressing no interest versus some interest in a patient visit, on age, psychological distress, social support, and attitudes toward fellow patient support.

Variables	No interest	Some interest	t value	df	*p*
N	28	56			
%	33.3%	66.7%			
Demographics					
Age	57.81	52.80	1.802	46	0.078
Psychological distress					
HADS:Depr	2.63	3.93	1.955	67	0.055
HADS:Anx	4.30	7.61	3.554	62	0.001 S
BDI	5.44	8.51	1.709	50	0.094
Support					
Family	5.52	5.27	1.139	65	0.259
Friends	5.19	5.02	0.636	67	0.527
Doctor	5.74	5.57	1.021	62	0.311
Attitudes toward fellow patient support					
Understand	2.52	2.84	2.572	39	0.014 S
Support	2.30	2.63	2.028	45	0.049 S
Other	2.63	2.73	0.810	45	0.422

APPENDIX C:

Psychiatry	% Used	No interest	Some interest	Strong interest
Total (n 84)	8%	83%	16%	1%
HAD:depr.(n 9)	11.1%	78%	22%	0%
BDI (n 17)	11.8%	71%	29%	0%
HAD:anx. (n 30)	13.3%	70%	30%	0%

Counselling	% Used	No interest	Some interest	Strong interest
Total (n 84)	12%	82%	16%	2%
HAD:depr.(n 9)	11.1%	78%	22%	0%
BDI (n 17)	17.6%	76.5%	23.5%	0%
HAD:anx. (n 30)	20%	67%	30%	3%

Social Work	% Used	No interest	Some interest	Strong interest
Total (n 84)	41%	69%	15.5%	15.5%
HAD:depr.(n 9)	55.6%	56%	22%	22%
BDI (n 17)	58.8%	53%	23.5%	23.5%
HAD:anx. (n 30)	53.3%	60%	17%	23%

Coping Skills	% Used	No interest	Some interest	Strong interest
Total (n 84)	7%	77%	12%	11%
HAD:depr.(n 9)	11.1%	56%	22%	22%
BDI (n 17)	5.9%	71%	12%	17%
HAD:anx. (n 30)	6.7%	60%	27%	13%

Professional G.	% Used	No interest	Some interest	Strong interest
Total (n 84)	10%	68%	15%	17%
HAD:depr.(n 9)	22.2%	44.5%	11%	44.5%
BDI (n 17)	11.8%	59%	17.5%	17.5%
HAD:anx. (n 30)	13.3%	53%	27%	20%

Lay Group	% Used	No interest	Some interest	Strong interest
Total (n 84)	13%	58%	17%	25%
HAD:depr.(n 9)	22.2%	44%	0%	56%
BDI (n 17)	17.6%	47%	6%	47%
HAD:anx. (n 30)	16.7%	40%	23%	37%

Informal G.	% Used	No interest	Some interest	Strong interest
Total (n 84)	11%	56%	23%	21%
HAD:depr.(n 9)	11.1%	56%	22%	22%
BDI (n 17)	11.8%	59%	12%	29%
HAD:anx. (n 30)	13.3%	50%	30%	20%

Patient Visit	% Used	No interest	Some interest	Strong interest
Total (n 84)	48%	32%	16%	51%
HAD:depr.(n 9)	44.4%	22%	11%	67%
BDI (n 17)	58.8%	23.5%	12%	64.5%
HAD:anx. (n 30)	50%	17%	17%	67%

✓ **APPENDIX D:**

PSYCHOSOCIAL CARE FOR PEOPLE WITH CANCER.

FOCUS GROUP DISCUSSION GUIDE
Time : 2 1/2 hours

INTRODUCTION AND WARM-UP (15 min.)

Welcome the group

Aim of group meeting
- Type of concerns people with cancer have to deal with,
- What can be done about these concerns? - Your feelings with regard to the different types of psychosocial care available to cancer patients.

Ground rules
- Focus groups - qualitative research
    - used to gain a deeper understanding about certain things
- No right or wrong answers
- Very important that I hear your views and opinions, my views are not important; you must take control of the discussion and you must tell me whatever you want to.
- Each one of your contributions is very important so please encourage everyone to speak.
- I am going to record our discussion because I will never remember all that was said afterwards, does anybody have any objections?
- Confidentiality: your names will not be noted, anonymity will be ensured.
- Whatever is said in this group stays within this group; we need to develop a trust so that we can be completely open and honest. There are no right or wrong answers so please feel free to speak out if you agree or disagree.

Introductions
- introduce each other

CONCERNS (45 min.)

- Word association: Cancer - What comes to mind (PROBE - identity and concerns)
- talk a bit about each of your experiences with cancer
    PROBE - get discussion going
        -"How did that make you feel?"
        -"How did you deal with that?"
        -"What do others think? Did you also experience such problems?"
- pass out list of concerns
    - are there any here that strike you as relevant?
    - Lets go through them

COPING WITH CONCERNS (15 min.)

- How did you deal with these concerns and problems?
- Role of support; family, friends, doctors, CANSA?
    Who was most important?

TYPES OF PSYCHOSOCIAL CARE (60 min.)

- Pass round list of services.
- Discuss each and probe
    - useful?
    - would you use it?
    - why not?
        - don't need it?
        - are there any other reasons why people don't use them?
            PROBE- make you feel uncomfortable?
- PROJECTIVE: what type of people use this service? Can you describe such people?
- What is missing?
- PROJECTIVE: I'd like to us to imagine a situation. We are now the administrators of the hospitals and general health services; we are the big shots, the people who determine what the system of health care looks like. We are having a meeting where we are designing what the health care system for cancer patients will look like. We have unlimited resources (except a complete cure for cancer). Let us start at the beginning:
    PROBE: From the patient's point of view, what happens to him or her? Staff (doctors, nurses)approach to patients, what other services are available.
    - Screening and diagnosis
    - Treatment
    - Follow-up, check-ups

CLOSING (15 min.)

- summarize main issues and points
- What can we do?
- Should we do anything?
- Is there any role for people with cancer, or who have had cancer?