# NEEDS, PROBLEMS AND STRESS OF RURAL CANCER PATIENTS: AN INTERPRETATION ACCORDING TO THE BIOMATRIX THEORY.

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Dedicated to my father Alwyn and my brother Warren who both achieved excellence in their own ways. Their memory is always an inspiration to me.

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ABSTRACT

The purpose of this study was to identify the needs and problems that were experienced by rural cancer patients and to investigate the level of emotional stress that they reported. A further purpose was to interpret the main findings of the study according to the Biomatrix Theory.

496 Cancer patients who lived in rural areas of the Western Cape and 140 urban cancer patients were interviewed. The urban cancer patients formed a control group for comparison of the stress data. In order to consider the needs and problems of rural cancer patients from a widespread area, stratified random sampling of magisterial districts was applied and an attempt was made to interview all cancer patients who were living in each of the 21 magisterial districts sampled. Data on needs and problems were collected by use of a questionnaire, and the stress data was collected by administering a modified format of the Stress Evaluation Inventory (SEI).

The findings of this study revealed that financial difficulties were the most frequently reported problem while transport difficulties and frustration of emotional support needs were also frequently reported. Patients who reported experiencing these problems also reported statistically significantly higher stress according to the SEI than those who did not.

In an attempt to understand the processes involved in the causation of these problems and the relationship between them and reported stress, the data was interpreted in th elight of the Biomatrix Theory. This interpretation revealed that relationships did exist between these three variables. These relationships appeared to exist because the purpose of each of these variables was directed at fulfilling needs within the cancer patient and in many cases they had to interact to achieve their objectives.

Only 17% of rural cancer patients reported difficulty in arranging transport to treatment centres. The cost of transport (as well as the cost of many other items) resulted in 50% of patients reporting strained and frustrated finances. This, together with psychological stress related to leaving home to attend treatment at distant hospitals resulted in patients experiencing undue stress and a lack of emotional support. However, most patients (91% of the rural cancer patients and 79% of the urban cancer patients) were able to receive emotional support even when they were separated from their families. According to the Biomatrix Theory the stress that was generated by the difficulties experienced was reduced through the interaction that patients had with their support systems.

Rural cancer patients did have problems relating to their geographical distance from treatment centres and these problems appeared to cause additional stress to patients.

The Biomatrix Theory proved to be a valuable tool in facilitating the qualitative interpretation of the results of this study.

# CHAPTER 1: INTRODUCTION

## 1.1 CHAPTER INTRODUCTION

In this chapter the disease aspects of cancer will be reviewed. The special areas of concern which have been investigated in this thesis will be introduced, and a rationale for the research will be provided.

## 1.2 OVERVIEW OF CANCER

Cancer is a common disease all over the world (Stjernsward, Stanley, Eddy, Tsechkovski, Sobin, Kozai & Notaney, 1968; Weisman, 1979). While not all people who contract cancer will die from it, each year some 4,3 million deaths are caused in the world by cancer (Stjensward et al., 1986). Affluent societies appear to be more at risk for cancer, although the incidence is thought to be masked in developing countries by the effect of communicable diseases (Maclennan, Muir, Steinitz & Winkler, 1978).

Even though cancer is a disease which is found commonly throughout the world, the incidence can differ widely in different areas. Incidences of cancer differ due to environmental factors, geographical location and the developmental stage of a country (Bradshaw, Harrington & McGlashan, 1983; Stjernsward et al., 1986). People from higher socio-economic groups have a higher risk for some types of cancer such as breast and colon cancer, while people from lower socio-economic groups are more susceptible to cancers such liver and uterine cervix cancer (Maclennan, Muir, Steinitz & Winkler, 1978).

Some other demographic factors which reflect differences in cancer incidence are age, sex and race. Cancer is more common in older people (Editorial, Cancer News, 1986; Maclennan et al., 1978; Levenstein 1980; Goddard 1986; Weinrich & Nussbaum, 1984), and this is illustrated by the fact that 50% of all cancers occur after the age of 65 years (Silverberg, 1982). Different types of cancers are more commonly found in a particular sex, eg. breast and cervical cancer is most common in women while lung, stomach

and prostate cancer is most common in men (Silverberg, 1982). A different incidence pattern has also been observed in various racial and national groups (Maclennan et al., 1978). This may be because of variations in cultural habits, socioeconomic status or the geographic homogeneity of some populations. Due to these trends it has been suggested by some researchers that it is more valid and meaningful to study cancer patients in appropriate groups (Maclennan et al., 1978).

Most people appear to have some risk for cancer and therefore even though advances in medical technology have provided cancer patients with an overall improvement in prognosis (Levenstein, 1980), cancer continues to be an important cause of death in the world (Fobair & Cordobac, 1982). Despite an increase in the incidence of cancer, more people respond to treatment and as a result aggregated death rates are constantly declining (Conkling, Christ & Fobair, 1986; Fobair & Cordobac, 1982). This improvement and advancement in cancer treatment is reflected in the 50% cure rate of localized lesions (Zubrod, 1975).

While these improvements in treatment methods have resulted in the prolonging of life for many patients, it has also highlighted that cancer is a chronic illness which can have a major disruptive effect on individuals and families (Fobair & Cordobac, 1982; Turks & Kerns, 1985). Like other chronic illnesses cancer can disrupt personal functioning, ability to continue working, family relationships, social relationships, financial stability, life style and value systems (Fobair & Cordobac, 1982; Norby & Johnson, 1985). When family members and those close to the patient are considered, a great many people's lives are touched by cancer and in each case this is a surprise and a personal tragedy to all concerned (Fobair & Cordobac, 1982).

Cancer is seen to be a tragedy because of the life threatening nature of the disease and because of the chronic suffering that it can bring. It is therefore

understandable that until recently, most of the emphasis in cancer care was devoted to technological advances that could prolong life and provide patients with as pain free an experience as possible (Schain, 1981; Lancaster, 1986). This has resulted in a situation where the present state of knowledge of cancer is mainly about the biological development and the treatment aspects of the disease. Even though there is no doubt that cancer is a psychosocial calamity (Weisman, 1979), relatively little is known about the impact of the disease on the patient's and the family's ability to function effectively (Fobair & Cordobac, 1982).

In recent years some researchers have shown interest in focussing more on quality of life concerns and this is to be welcomed (Nerenz & Love, 1986). This interest in psychosocial issues developed out of the rise in psychosomatic research. Psychosomatic medicine began with investigations of the effects of psychological factors such as emotional stress on the body. An alternative approach, which is to investigate the individual's reaction to physical illness rather than the somatic response to experiences of life (Anastasi, 1979), is the approach that is taken in this study. The purpose of this approach is to investigate ways to improve patients' coping abilities to enable them to interact effectively with their environment and with their family and friends (Schain, 1981).

## 1.3 AETIOLOGY OF CANCER AND PSYCHOSOCIAL RESEARCH

Considerable research has been done on the possible causes of cancer. Causative agents can be individual factors or combinations of factors and include industrial pollution, smoking, diet, radiation exposure, carcinogenic chemicals, stress and personality factors (Fobair & Cordobac, 1982; Le Shan, 1977; Panagis, 1982).

While the subject of 'response' to cancer is not yet well documented, the role of psychological factors in the pathogenesis of cancer has been a subject of inquiry for centuries (Panagis, 1982). Most of the interest has been in identifying premorbid personality attributes of persons

who contracted the disease (Panagis 1982). Researchers who propose that there is a cancer prone personality include Girdana and Everly (1979), Le Shan (1977) and Simonton and Simonton (1975). Researchers such as Cohen (1979), Fox (1982) and Wellish (1983) feel that the available evidence does not suggest that there is such a personality. They criticize the research methods that are generally used in that they are frequently of a retrospective nature thereby minimising predictive power. The variability in the interpretation of stress by patients and the contradictory findings of much of the research raise serious doubts that the existence of a cancer prone personality exists (Cohen, 1979; Eysenck, 1988; Fobair & Cordobac, 1982; Wellish, 1983). However there is too much empirical evidence to doubt that some cancers are caused by the interaction of stress with personality in a "synergistic interplay". Though the "synergistic interplay" is still to be worked out, destructive behaviours such as smoking may be initiated and maintained by psychological stress (Eysenck, 1988; Wellish, 1983).

While the role of stress and personality factors in the cause of cancer has been well documented it was only in the late 1960s that research into the behavioural aspects of coping with cancer became more common. This field of study was led by Elizabeth Kubler-Ross who pioneered research into the emotional aspects of dying (Kubler-Ross, 1969). Even though she studied patients who were dying from a variety of chronic illness, she used the dying cancer patient as the central figure in the development of her theories. In the proliferation of literature that was generated from her work, researchers extended her ideas, but continued to focus on cancer patients who were in the process of dying.

Other areas of research involving psychosocial considerations include the relationship between stress and the immune system in the causation of cancer and the effect of stress on response to treatment (Eysenck, 1988). While it is not yet conclusive, it is thought that chronic stress

may slow down the growth of cancer because it stimulates the immune system, while acute stress is suspected of promoting the growth of cancer (Eysenck, 1984; Kennedy, Kiecolt-Glaser & Glaser, 1988).

In general, very little attention has been paid to cancer patients who are receiving treatment but are not necessarily in the terminal stage of the illness. Because of the chronic and complex nature of the disease, these patients experience many practical, medical and emotional problems over a prolonged period of time. The relationship between the problems that they experience and their ability to cope are critical factors in determining the quality of life that they experience.

## 1.4 AREAS OF INVESTIGATION IN THIS STUDY

The areas of concern for this study are the needs and problems encountered by rural cancer patients and the psychological stress that these patients experienced.

As cancer is a complex and serious disease, cancer patients have to face a wide variety of problems and challenges which can threaten their quality of life (Nerenz, 1986). A good quality of life is dependent on factors pertaining to the environment, society and on factors of subjective significance to the individual. Existential concerns such as work, self appraisal and anxiety about health have been reported as important concerns for cancer patients regardless of the site, stage or type of cancer that they have (Weisman, 1979)

Problems that patients experience frequently arise out of unfulfilled needs which are important to patients' abilities to adjust or to their quality of life. Needs compete for attention in a living system and can cause stress and strain until they are resolved (Lane 1986). Nerenz (1986) says that expressed needs can be seen as unmet needs and not necessarily the most important needs, which may already be satisfied. Patients who have unmet needs can be said to have problems, and for the purpose of

this study the terms "needs" and "problems" are used in this way.

The needs and problems that cancer patients experience require immediate attention otherwise severe distress can occur. Cancer is a threat to patients' life styles and is also a threat to life itself (Schain, 1982). Notwithstanding the practical problems that may confront dying patients, the emotional phases of life threatening illnesses bring their own difficulties (Wright, 1985). A wide variety of theories are suggested as good explanations of the phases that patients go through as part of the process of coming to terms with chronic illness. In general theorists seem to agree that shock and anxiety characterize the acute phase, frustration, anger and physical and practical difficulties the chronic phase and anxiety, grief and withdrawal the terminal phase. The challenges that patients have to confront in this process places a tremendous burden on the patient's coping resources. These resources may already be strained due to the many changes and adaptations that cancer patients have to make in their lives (Janis, 1969).

It is very important for cancer patients to have the ability to cope with stressful situations because they are constantly exposed to problems and if they are extremely stressed, coping and adjusting becomes very difficult (Weisman, 1986).

Besides the problems of coping and adaptation that are experienced as a result of having cancer, rural cancer patients have many additional problems. These problems are due to the physical distance between themselves and the health care services that they need (Searle, 1986), and also due to the lack of support that can result from extended periods spent away from home. Ideally health care services should be planned and based according to patients' needs (Nerenz, 1986), but this is not always financially or practical possible.

Isolation from the family is an important problem due to the important role that the family plays in absorbing the stresses and strains that its members experience (Turk & Kerns, 1985). The interaction between the family's problems and their available resources determines the degree of stress that will be generated in the family system. It has been reported in previous research that cancer patients who receive, or even expect, little support from their families experience higher stress that those who receive and expect support (Stoll, 1986; Weisman, 1979)

Fortunately not all people are at high risk for distress. This is often dependent on the resources that patients have, with poor resources indicating a high risk factor (Weisman, 1979). The most valuable resource that patients can have is the emotional support of their families (Stoll, 1986) and the fact that adjustment problems are common in chronic illness (Springer, 1985) may be because modern social and family support systems are not always effective (Stoll, 1986).

It is because of their importance to cancer patients (Cartwright & Cartwright, 1971; Schmale, 1982) that stress, coping and relevant practical factors were investigated in this study.

## 1.5 APPROACHING THE STUDY OF CANCER PATIENTS

Neither the inception of cancer nor it's progression can be viewed as isolated medical events in the life of a patient (Schweitzer, 1982). Because the body and the mind are part of one living system, when a person becomes ill from cancer, besides the growth of cancerous cells in the body the response of the patient to illness is just as important (Bresnick, 1981; Viney, Clarke & Benjamin, 1986).

Cancer patients are exposed to many new systems such as hospitals, medical staff and other patients and have to adapt to these new situations to reduce conflict and stress that might be experienced (Schmale, 1982; Viney et al., 1986). In the study of stress and adaptation it is

important to use techniques that accommodate the analysis of complex and dynamic processes (Lazarus, 1982; Schmale, 1982; Viney & Westbrook, 1987). In analyzing the processes involved in the relationships between stress, adaptation and cancer, a more holistic conception of health and healing is needed than what the traditional medical model provides (Kris, 1981; Panagis, 1982). By including the disease, family, cultural and personal factors when approaching cancer patients, the maintenance of wholeness of the person and a better understanding of their experiences is achieved (Kris, 1981; Viney et al., 1986). However Weisman (1986) cautions that the authenticity of the holistic approach depends on the blend of generality, specificity and relevance of factors to the individual patient while, Goddard (1986) suggests that people function in relation to their environment and that no theory accommodates this better than the holistic approach.

Philosophies comprising the holistic health movement generally hold that positive and good life style creates "health", meaning "wholeness". Capra (1987) says that by concentrating on the notion of the body as a machine, of disease as the consequence of breakdown and of the doctor's task as repairing, modern medicine often looses sight of patients as human beings. Carl and Stephanie Simonton, a radiation oncologist and a psychotherapist have pioneered the way in uniting psychotherapy, formal medicine and holistic health movements. They established a Cancer Counselling and Research Center, and proposed traditional treatments plus active participation by patients. They suggested that patients participate in their own health by personal action and the modification of attitudes, belief and feelings (Kris, 1981; Simonton & Simonton, 1975).

It has been suggested by Prof Tim Noakes (1985) that we know too much about disease and the limitations of the human body and too little about it's enormous potential. He states that we have yet to learn that there is a healthy way to be ill.

## 1.6 RATIONALE FOR THIS STUDY

Cancer is a common and formidable illness in the South African context. It is the second most frequent cause of death in whites with the incidence in other groups lower but steadily increasing (Bradshaw & Harrington, 1975; Robertson, 1969).

The conventional, and most commonly used, cancer treatments require a high degree of professional specialization as well as expensive and cumbersome equipment (Nerenz & Love, 1986). Treatment and diagnostic assessment generally takes place at large and sophisticated city hospitals (Brown & Kiss, 1980). Straight forward diagnostic or surgical procedures are performed in smaller rural hospitals but this is not common, and patients are inevitably referred to the larger centres for further assessment or treatment.

A large proportion of the South African population live outside of the major metropolitan areas, some in very distant and isolated regions. Due to this the key issues for rural cancer patients are accessibility and availability of treatment as well as the the implications of having to travel for treatment or care (Parrot & Theeman, 1982; Young, 1986). Huessy (1972) states that while urban and rural patients share some similar problems they clearly differ in aspects such as wealth, isolation, lack of medical resources and absence of continuity of health care. A further problem concerning rural areas is that the incidence of cancer tends to be underestimated due to the under reporting and the unreliability of diagnosis (Huessy, 1972; Searle, 1986). This has important implications for the planning and co-ordination of medical care and resources, and means that rural areas will tend to be undersupplied.

While research on specific aspects of cancer nursing, scientific, technical and medical areas have been done in South Africa, no previous research has been published in

the area of problem and stress assessment of the rural cancer patient. Three studies have been undertaken in America to investigate unmet needs of cancer patients. Two of the studies, one by Hawes (1982) and the other by Ramsey and Hawes (1982), focussed on cancer rehabilitation and continuing care leading to the development of training programmes and community based interdisciplinary oncology teams. The third study was conducted by Rose, Kirkpatrick, Gaber and Pories (1979) and examined terminally ill rural patients and considered practical problems encountered by health care professionals.

In addition to these three studies, the literature appears to detail a wide variety of investigations into many diverse factors concerning cancer patients. Little effort has been made to explore the possible needs and problems of the many rural patients in the world or in South Africa. This is perhaps understandable when one considers how expensive in time, money and effort this kind of research is. The need for a variety of care in rural areas is clear, but the difficulty in doing the necessary scientifically acceptable research makes motivating and planning for these improvements very difficult.

Due to the nature of the disease and the complications resulting from treatment, it is hypothesized that rural cancer patients are practically, medically and emotionally disadvantaged (Kutchenhoff, 1981) because of their geographical distance from major treatment centres and helping resources. This study will attempt to contribute to the existing literature by examining the most commonly found problems reported by rural cancer patients (of the Western Cape), and to examine the level of stress that they experienced. The design of the study was of a cross-sectional nature and questionnaires were selected as the method of data collection. Questionnaires were selected because they are useful when a wide variety of questions are being asked and when large samples are distributed over a wide area (Brink, 1986; Simpson, 1984).

## 1.7 CHAPTER SUMMARY

Cancer is a common disease in the world and in South Africa. As a disease it has a drammatic effect on all aspects of patients' lives. Problems or unmet needs that patients experience provide a challenge to them and their supporting systems to adjust and cope. The extent to which patients manage to adjust can be seen by the stress that they experience. The stress and strain that patients feel can determine their quality of life at this critical time in their lives. Rural cancer patients have additional difficulties because of their isolation from specialized treatment and care, and valid and reliable research is necessary to promote the improvement of the situation. It is important to approach cancer research in such a way that the patient's response to their illness is not viewed from a purely biological viewpoint but rather in a holistic way.

# CHAPTER 2: NEEDS AND PROBLEMS OF CANCER PATIENTS

## 2.1 CHAPTER INTRODUCTION

In this chapter the relationship between problems and needs will be considered. An overview of the literature on problems that cancer patients commonly experience will be given. The special problems of the rural cancer patient will also be highlighted.

## 2.2 DEFINING NEEDS AND PROBLEMS

Health is an ongoing process involving physical, psychological and social factors. To be healthy individuals need to be flexible to be able to adapt to environmental changes (Capra, 1987).

Capra's ideas highlight the complex and dynamic interplay of needs, adaptation to environmental demands with the ultimate desire to function well. A need of a living system is a lack of a specific resource which is useful or required by the purpose of that system. A resource may be matter (eg. food, money), information (eg. knowledge about the disease or other resources) or energy (eg. stamina, assistance, effort) (Lane, 1986).

In the context of this study needs represent the status of various matter-energy and information resources in accordance with the purpose and objectives of rural cancer patients. A need is a construct which explains behaviour and is usually unobservable (Lane, 1986). Researchers are therefore usually dependent on the patient's report of what is needed when gathering data. Needs fluctuate widely in a living system and can compete for attention. What is not very important one day (eg. need for a pain killing tablet) may be an urgent need on another day. When needs are not satisfied or met, a "lack" in the system occurs and this causes stress and strain in the person (Lane, 1986). For the purpose of this study, when this happens, it will be accepted that a need has developed into a problem.

A more technical and detailed account of the transfer of stress in and between systems will be given in the chapter on the Biomatrix theory in this thesis.

## 2.3 PROBLEMS EXPERIENCED BY RURAL CANCER PATIENTS

The wide range of complex problems that rural cancer patients experience can be related to medical, practical or emotional issues (Conkling et el., 1986). Cancer requires ongoing adjustment for individuals and families (Edstrom & Miller, 1981). Blumberg states that "the major challenge in coping with cancer is coping with the illness and its attendant problems, and also coping with life as it is altered by the illness" (1981 p5).

Cancer, and the way that it presents is in itself a problem. It is generally an unexpected and shocking event which poses a serious threat to life in the way that the individual knows it. Cancer is a feared disease and the stress that this generates is compounded by the negative Western attitude to death (Garfield, 1975). Besides being equated with death, in many societies cancer also represents a social stigma which patients have to tolerate (Edstrom, 1981). Serious illness such as cancer causes severe stress in the family system. This is due to the fact that past family roles may no longer be appropriate and many adjustments may have to be made by the whole family.

2.3.1 Practical considerations: Illness of any kind can be a source of socioeconomic hardship in the rural setting (Mabogmje, Grundy & Lawrie, 1980). Making practical arrangements to travel, be absent from work etc. can be difficult and tedious. These chronic and tedious problems can result in patients avoiding attending distant treatment clinics with possibly fatal results (Kalish, 1981; Mabogmje, Grundy & Lawrie, 1980). Besides problems caused directly by cancer, Mary Vachon (1986) reports that most of the cancer patients she studied were dealing with many other stressors in their lives. Some of these problems included work, school, home-making, family and marital

relationships.

Cancer should be viewed as a chronic illness where adaptation to the simple problems of daily living are important (Schain, 1981; Silberfarb, 1982). There is considerable agreement that the most commonly reported concerns are work and employment, social and leisure restrictions, effect on the family and concern for psychological adjustment (Schain, 1981; Weisman, 1979). Of these concerns finances and work related issues seem to be the most worrying to cancer patients (Springer, 1985; Zubrod, 1975; Kalnins Churchill & Terry, 1980; Comazzi Barbieri & Tabiadon, 1981; Barton Coombs & Birmingham, 1979). In a study by Johnston (1986), among factors of age, socioeconomic status, financial problems and interpersonal disruption only financial problems were significantly related to stress. The depletion of resources over an extended time can have a long-lasting and deleterious effect on all family members. Family members may be deprived of basic needs in order that some service can be provided to the family. Financial concerns are very real and many people have faced bankruptcy and psychosocial deterioration for seeking the best possible care available (Fobair & Cordobac, 1982).

Besides direct medical costs which can be a burden to cancer patients (Elovanio, Hosti, Taskinen & Vontilaines, 1977), expenses such as sheepskins, wigs, walking aids and special pillows are also an important consideration. Previous studies (Fobair & Cordobac, 1982) revealed that 50% of patients spent 25% of their annual income on indirect costs such as transport, special equipment, loss of income and other non medical expenses.

Besides the financial worries, work stressors include being overwhelmed by responsibilities or not being able to do the work satisfactorily (Musci, 1985). Work can be an important source of personal identity and self realization. This is of particular significance to patients who are part of a Western culture, where financial

and psychological independence are highly valued and loss of work can mean loss of status (Cooper & Baglioni, 1988; Fobair & Cordoba, 1982).

Due to the fact that race has been found to be associated with socioeconomic status, special attention must be given to the practical needs of groups who are most likely to be disadvantaged (Miller & Riessman, 1972; Lewis, 1985). So called `coloureds', `blacks' and some `non-white' immigrant groups have been seen to be discriminated against, and tend to occupy lower paying jobs (Braddock, Crain, McPartland & Daekins, 1985; Fosser, 1986; Greenberg, 1984; Lewis, 1985).

Other problems that rural patients are frequently confronted by and which relate more directly to their illness are access to supportive professional staff, poverty, transport inadequacies, geographical isolation and equipment needs (Barton, Coombs & Zakanycz, 1979; Rose et al., 1979; Webster, 1986).

Almost all rural cancer patients have to travel to treatment centres, and they experience a wide variety of difficulties in their individual experiences (Edwards, 1987; Huessy, 1972). In a study by Maisiak, Games, Lee and Jones (1982), travel problems were one of the most frequently stated reasons why rural cancer patients missed treatment appointments. However, research by Rose et al. revealed that transport is not always a major problem for patients. This may be because most rural cancer patients try to do whatever they can to stay at home for the duration of their illness (Rose et al., 1979). For cancer patients who need palliative care, it is not only cheaper for them to be at home rather than in hospital, but their families have a valuable role to play in their care (Edstrom & Miller, 1981; Rose et al., 1979; Woodhall, 1986).

While the importance of practical problems for rural cancer patients is acknowledged in the literature, where it is

mentioned it is done in a rather superficial way with little in-depth study. If a unified and holistic treatment plan is to be devised for cancer patients, information on environmental considerations must be collected and included (Mannes, 1982).

2.3.2 Medical Considerations: The absence of specialized consultation regarding symptom and complication management of cancer is a major problem for patients who live in geographically distant areas. Difficulties surrounding the feedback and follow-up of patients who have been treated in the city and then return to their rural homes needing continuing care, have been the concern of oncologists for some time (Tanabe, Itano & Iwemoto, 1983).

It is very difficult to separate the symptoms of cancer and the side effects of the treatment if any is being received. Conventional treatments include surgery, radiotherapy, chemotherapy and occasionally immunotherapy. The side effects of surgery and radiotherapy are short lived compared to that of chemotherapy, which can produce severe and debilitating symptoms during the periods when the treatment is being administered. The most commonly experienced side effects are nausea, vomiting, lethargy and alopecia. Clement-Jones (1985) reports that emotional problems are much more commonly found in patients who are receiving cancer treatment than those who are not.

Like all cancer patients, major problems which are experienced by rural cancer patients are pain and nausea. These problems can be complicated by the rural setting because of the local health care professionals lack of expertise in dealing with them. Nearly 50% of advanced cancer patients have no pain, 10% have mild pain and 40% have severe, continuous and disabling pain (Allbrook, 1985). Cancer pain can be unremitting and if unrelieved can severely traumatize the patient and the family (Allbrook, 1985). However, cancer pain and nausea can be well controlled by current medical methods. Modern pain

management includes emotional support, symptomatic pain relief, pharmacological supplementation and elimination or reduction of the tumor. The essence of successful pain control is individual timing, accurate administration and the prescription of the correct analgesic. The nature and the severity of the pain and the condition of the patient will determine the drug to be employed. With the implementation of training and education there is reason to suggest that this can be done effectively in the rural setting (Allbrook, 1985; Lancaster, 1986; Raven, 1986; Swerdlow & Stjernsword, 1982).

One of the most commonly reported needs which related to the area of medical management concerned the patient's need for additional and accurate information about their cancer. Most patients wanted to know as much as possible about their condition even if the news was bad (Clement-Jones, 1985; Editorial, 1986; Ley, 1981; Nerenz & Love, 1986; Rose et al., 1979). This often leads to misunderstanding and conflict with medical professionals and even a struggle for control as health care providers try to manage the clinical situation and patients try to play an active role (Ley, 1981; Sullivan, Devine, Bowen-Thomas & Tattersall 1986; Vachon, 1986). If patients are to contribute to their treatment by a participatory response, they need to have more information so that they can feel that they have some control over the situation (Garfield, 1979).

Cancer is often regarded as an "older person's disease" because statistics show that the older a population becomes the higher the incidence of cancer (Editorial, 1986). For this reason complications of aging such as weakness, loneliness, backache and constipation can be additional problems for some older patients to deal with. Problems such as the type and range of care for the aged must also be considered as not all elderly people have a warm and loving family to care for them (Goddard, 1986; Mugford & Gobson 1986). However, on the positive side, elderly patients have been reported to be less depressed and more

socially adjusted to their cancer than younger patients (Maisisk, Gams, Lee & Jones, 1982).

Most patients who have cancer have a need to be nursed and cared for whether this is while they are in the process of being treated or whether they are in the terminal phase of the illness. These needs are not easily met in the rural setting where the nursing and equipment resources are very limited (Edstrom, 1981). Equipment needs were reported in many studies (Edstrom & Miller, 1981; Rose et al., 1979; Webster, 1986). The special equipment that chronically ill and patients who are confined to bed need to make their lives comfortable include special pillows (to make lying in bed more comfortable), bed pans and urinals (to facilitate toilet needs), medical sheep skins (to prevent bedsores), walking frames (to aid the patient's mobility), wheelchairs and many others.

2.3.3 Emotional Considerations: There are many emotional factors concerning the patient and his family's response to cancer. These include response to diagnosis and treatment, social attitudes, perhaps dealing with approaching death and problem situations which can provoke psychological stress (Anastasi, 1979). Blumberg (1981) states that there is no pattern to emotional reactions to cancer, and that studies investigating this area generally have methodological shortcomings. The most important emotional consideration appears to be the area of emotional support and the role that the family plays in supporting the patient (Oberst, 1980).

Emotional support refers to behaviour which assures the individual that they are loved and valued regardless of any achievement that they make or fail to make (Bloom, 1982). Emotional support is usually provided by a primary group such as the family or family members. Emotional support is required constantly by individuals who are experiencing a chronic stressor such as cancer. This has further implications for the rural cancer patient who has to travel away from friends and family to distant treatment centres

for extended periods of time. These patients frequently feel alone without the support that they need, and can suffer extreme anxiety and distress (Bloom, 1982; Hartland, 1985; Oberst, 1980).

There is much literature on social support systems, but Bloom (1982 p129) states that it is "diffuse". The literature seems to cover subjects such as the support which should be provided by professionals, rather than individual experiences of support (Breslow Copley & Lilienfield, 1976). Research into the monitoring of emotional responses of patients has been aimed mostly at their experience of depression and anxiety (Lee, 1986).

The family are usually the `providers of support' for the cancer patient, although this role can also be played by close friends, neighbours or colleagues (Pilisuk & Parks, 1983; Woody & Springer, 1985). Support is important to cancer patients in that it enables the patient to feel secure and reassured (Springer, 1985). This is achieved by providing the patient with emotional support and making resources available to the patient to help with the satisfying of needs and the solving of problems (Bluglass, 1986; Cohen, 1982). To enable this process of support to take place effectively, patients should have good relationships with the people who are supporting them (Vachon, 1984).

Because of their isolation, rural cancer patients are frequently denied the opportunity to benefit from support from other cancer patients or professional counsellors (Tache, 1979). Little emotional support seems to be provided by health care staff to cancer patients (Hartland, 1985). This apparant lack of support is a serious problem, since the relationship between the patient and the medical team plays an important role in the patient's response to treatment (Anastasi, 1979). Bloom (1981) suggests that the two forces that militate against support from the medical professionals is the high degree of specialization as well as the focus on treatment of the

illness rather than the person.

When in the hospital situation it is important for patients to share their feelings to sort out their concerns and frustrations (American Cancer Association, 1985). While supportive staff who are open to the sharing of good relationships, could add to the patient's sense of security (Webster, 1986), clinical staff are not really trained to deal effectively with the wide range of emotional needs that cancer patients have (Pollard, 1986).

Because of the isolation from treatment personnel it is important for rural patients to have a relationship of trust with their local doctor to ensure continuing care (Rabin & Wulf, 1985). Effective teamwork in the community health care system is essential to provide the patient with confidence and support (Editorial, Medical Chronical, 1985; Oberst, 1980; Schreier & Dub, 1980).

It has been suggested that emotional support facilitates the patient's adjustment and that lack of support has been associated with "not coping" and failure to adjust (Bloom, 1981; Cain, 1979; Lee, 1986). The implications of patients being emotionally distressed are not clearly understood, but certain professionals believe that this may be a contributing factor in response to treatment (Conkling et al., 1986; Lee, 1986; Simonton & Simonton, 1975).

Anxiety and stress can be significantly reduced by the presence of emotional support from the family and especially the patient's spouse (Bloom, 1982; Kalnins Churchill & Terry, 1980). Clearly the family and their resources can play a critical role in providing the rural cancer patient with emotional support although this is not easy if good pre-existing relationships did not already exist in the family (Comozzi, Barbieri & Tabiadon, 1981; Turk & Kerns, 1985). The patient's family can provide emotional support not only by loving and caring, but by also making their financial, problem solving and other resources available to the patient (Ganster & Victor,

1988; Turk & Kerns, 1985).

All patients benefit from interest and empathy, and therefore emotional support is very important to cancer patients for the effective managing of stressful life events and for optimal functioning and a good quality of life (Brewin, 1986). Emotional support appears to play a stress-buffering role for rural cancer if it is supplied by the patient's close family system (Suls, 1982).

## 2.4 CHAPTER SUMMARY

There is a complex dynamic interplay between cancer patient's needs, their adaptive ability and environmental demands. The frustration of important needs and the rise of problems will result in distress for the patient. From an analysis of the literature the most significant problems that have been found in rural cancer patients include transport difficulties, financial problems, ineffective symptom control and emotional support. In general the literature is diverse and with only a few studies which examine these concerns in any depth.

# CHAPTER 3: STRESS AND CANCER PATIENTS

## 3.1 CHAPTER INTRODUCTION

In this chapter the concept of stress will be discussed. Trends in research into stress, the sources of stress and how people deal with it will be outlined. The relevance of stress for the rural cancer patient will also be reviewed.

## 3.2 RESEARCH AND STRESS

Stress is an extensively and diversely researched topic in the social sciences and affiliated medical disciplines. Yet little research has been done on psychological stress and illness (Cooper & Crown, 1988).

Although rooted in laboratory experiments, stress research has extended rapidly to naturalistic and humanistic settings (Crown, 1985). The concept of stress has been used in a variety of ways by researchers from different fields without co-ordination. As a result there is no clear and generally accepted definition of stress in the literature. The poor understanding of stress has been conpounded by the fact that research into stress has generally been done by psychologists and psychiatrists while research into the physiology of illness has been done by physicians (Capra, 1987). Therefore, because of the division between disciplines, stress as a cause or as a response to illness, has been relatively ignored by researchers (Anastasi, 1979).

In those studies where stress and it's relationship with illness has been examined, the most commonly used method has been to study somatic effects of psychological factors on illness. The alternative approach is to study stress as a reaction to physical illness and the associated adaptive ability that people need to have. This is a relatively unexplored area of research although it appears to be attracting increasing interest because of it's practical implications (Anastasi, 1979). Anastasi (1979)

states that in the field of cancer research and emotional stress, a few studies have investigated patients' responses to surgery, to types of treatment most likely to be psychologically disruptive and to hospitalization, but few have looked beyond these topics (Anastasi, 1979).

## 3.3 WHAT IS STRESS?

Stress has been conceptualized and defined in many ways. Lazarus (1982) stated that stress could be best understood as a broad field of study under which a wide assortment of problems and subjects can be researched. However this heterogeneity of focuses has raised the question of whether the concept of stress is meaningful or not (Novaco & Vaux, 1985). Novaco & Vaux (1985) suggest that a definition of stress is not important as it would tell us little about the nature of things but rather about the rules for the use of the word in language. However, other researchers have thought it important to try to define stress. Hans Seyle (Dionysius, 1988), defined stress as a nonspecific response which the body produces to any demand, while Milne, Burdett and Bekker (1986) said that stress was any demand which taxed the coping resources of an individual.

In preference to defining stress Capra (1982) explains it in terms of systems philosophy and holism. However, he states that the concept of 'stress in systems' can only be fully grasped when the subtle interplay between body and mind is perceived.

> "Stress is an imbalance in response to environmental influences. Temporary stress is an essential aspect of life, since the ongoing interaction between organism and environment often involves temporary losses of flexibility. These will occur when the individual perceives a sudden threat, or when it has to adapt to sudden changes in the environment or is being strongly stimulated in some other way. These transitory phases of imbalance are an integral part of the way healthy organisms cope with their environment, but

prolonged or chronic stress can be harmful and plays a significant role in the development of many illnesses."(Capra, 1982 p356).

To summarize the psychological viewpoint, stress can be seen as the condition of the individual or system that signifies a state of imbalance between demands and resources. Stress is therefore a hypothetical construct defined only in terms of an organismic response (Novaco & Vaux, 1985).

## 3.4 SOURCES OF STRESS; THE SYSTEMS APPROACH

In terms of the systems approach the natural balance of living organisms includes a balance between their self-assertive and integrative tendencies. A healthy organism has to be flexible to be able to integrate itself harmoniously into larger systems while retaining its individual autonomy. Stress occurs when one or several variables of an organism are extended to their extreme limits which induces increased rigidity throughout the system. In a healthy system other variables in the individual will move to restore flexibility and bring the whole system back into balance. Once the individual has taken action by fighting or fleeing, they will return to a state of relaxation and relative homeostasis. When an individual cannot be released from a stressful state by fighting or fleeing, it is likely to be detrimental to physical and mental health (Capra, 1982).

A second systems approach to the cause of stress is by Novaco and Vaux (1985). It shows many similarities with Capra's views. Novaco and Vaux suggest that stress is induced by environmental demands that exceed coping resources, thus disturbing homeostatic balance. They say that stress is manifested by adverse cognitive, behavioural and physiological consequences resulting from exposure to excessive environmental demands. Environmental demands are thought to operate in transaction with the behaviour of individuals or systems with the result that their effects are not uniform across individuals or systems, but are

mediated by unique cognitive, behavioural and social factors. Therefore stress is regarded as a product of contextually linked person-environment impact mechanisms, which determine how environmental demands are experienced (Novaco & Vaux, 1985).

In both Capra's (1982) and Novaco and Vaux's (1985) views, the initial factor in the stress process was some demand that was made on the system and the resulting stress was dependent on the system's unique response and ability to adapt.

## 3.5 ADAPTATION TO STRESS

Life changes, whether favourable or unfavourable demand adaptation and may elicit varying degrees of stress. The effect of these stressors differs greatly between individuals. This is because the type and amount of adjustment in life pattern that is required as well as the individual's resources for coping with the crisis will influence the impact of stressors (Anastasi, 1979).

In the face of threatening or stressful circumstances people react with a great variety of adaptive patterns that help maintain psychic equilibrium (Blumberg et al., 1981). Weisman (Webster, 1986) says that coping is about what an individual does about a problem to relieve it. Lee (1986) states that coping is an action directed at mitigating a problem situation, while Novaco and Vaux (1985) state that adaptation and coping are inherent parts of this stress process. Authors such as Silberfarb (Lee, 1986), Blumberg, Ahmed, Flaherty, Lewis and Shea (1981) draw a distinction between the terms coping and adaptation when discussing responses to stress. Silberfarb (Lee, 1986) regards adaptation as a more suitable concept because he feels that coping suggest an acute problem while adaptation suggests mastery. In fact he says that coping is adaptation under difficult conditions. Blumberg et al. (1981) define the terms separately but use them interchangeably, and suggest that effective coping involves successful adaptive behaviour.

Cancer is a chronic illness and adaptation is the central concept of adjusting to this process (Silberfarb, 1982; Tache, 1979). The two major functions of coping and adjusting are to change or improve the situation and to manage stress. The situation can be improved by the individual changing the action or by changing a threatening environment. Managing stress involves controlling stress-related emotions and responses to stressful situations so that anxiety does not rise and damage morale and social functioning (Lazarus, 1982). People's coping patterns differ, and sometimes palliative coping such as denying, intellectualization or avoidance can reduce stress and make patients feel better even though the person-environment relationship has not changed (Lazarus, 1982).

The ability to adapt to a changing environment is an essential characteristic of living organisms and of social systems. Systems are flexible and have a large number of options for interacting with the environment through regulatory feedback mechanisms. These options do not only involve adaptation but can include positive action such as relaxation, visualisation and meditation to help the system cope with stress (Capra, 1982; Sullivan, Devine, Bowen Thomas & Tattersall, 1986).

## 3.6 RELEVANCE OF STRESS FOR CANCER PATIENTS

Cancer engenders unusually high anxiety in most patients because of a number of factors. Some of these factors are that many commonly used cancer treatments require a high degree of professional specialization as well as expensive and cumbersome equipment (Nerenz & Love, 1986). Treatment and diagnostic assessment generally takes place at large and sophisticated city hospitals (Brown & Kiss, 1980). Straightforward diagnostic or surgical procedures are performed in smaller rural hospitals but this is not common, and patients are inevitably referred to the larger centres for further assessment or treatment.

A large proportion are related to the fear of dying

(Anderson, 1978). Webster (1986) states that emotional distress in patients who are dying is much greater than generally realized.

Vachon (1984) says that cancer is a stressful life event and in response, the whole human system has to make many adaptations. Sources of stress overload can originate with the individual, be generated collectively by society or produced by the patients physical environment. Stressful events can occur with some warning or very unexpectedly (Anastasi, 1979; Blumberg et al., 1981). The ability of cancer patients to bring tension and stress within comfortable limits is important to their quality of life (Anderson, 1978). Because of the social and media exposure that cancer receives, patients sometimes respond to the symbolic and social interpretation of cancer rather than to their own experience. This can result in patients responding to cancer by interpreting the situation as stressful and seeing themselves as overwhelmed and unable to cope (Anderson, 1978; Cohen 1979).

Weisman (1986) illustrates the broad implications of cancer in his statement that "cancer can drain the emotions as it can deplete finances" (p4). High levels of chronic stress in cancer patients can have a devastating effect on their lives (Anderson, 1979). It has been suggested that in an attempt to reduce these levels of stress, research should be done on reactions to diagnosis, hospitalisation and cancer treatment (Anastasi, 1979). Anastasi (1979) says that this is a very important and yet underexplored area of psychological research.

The way in which people adjust to the complex patterns brought about by cancer depends to a large extent on their pre-illness personality. Coping with cancer begins with patterns of coping and adapting to stress that people have integrated into their personalities. The individual who has had difficulty coping with life stresses may have difficulty coping with the discomforts and frustrations caused by having cancer (Anastasi, 1979; Blumberg et al.,

1981).

## 3.7 CHAPTER SUMMARY

Stress is the system's response to demands that exceed it's coping resources. Stress often occurs in a system as a response to some change or problem which requires coping and adaptation. Adaptation is a dynamic process and how it occurs depends on the type and amount of stress that is experienced. Besides being essential for all living systems, adaptation is very important for cancer patients. Cancer patients have to adapt to bring tension within tolerable limits to enhance their quality of life.

# CHAPTER 4: HOLISM, SYSTEMS THEORY AND THE BIOMATRIX

## 4.1 CHAPTER INTRODUCTION

In this chapter an explanation of the origins, dynamics and the application of the Biomatrix Theory will be given. The concept of holism will be briefly outlined, and a brief overview of General Systems Theory and systems theories in general will be provided. The Biomatrix Theory is a currently evolving framework in the area of systems theories. It is an important framework in that it attempts to answer some to the questions, and solve some of the critical problems that have plagued the systems approached for the past fifty to sixty years.

## 4.2 INTRODUCTION TO HOLISM

To some theorists the idea of holism represents the theory that an analysis of separate parts does not provide a total understanding of the functional whole (Bullock & Stallybrass, 1977; Katakis & Thomassin, 1988; Viney, Clark & Benjamin, 1986). The concept has evolved since the beginning of this century and amongst others, its very earliest proponents were Teilhard de Chardin, Alfred North Whitehead and Jan Christiaan Smuts (Jaros & Cloete, 1987; Poynton, 1987; Vetere, 1987). Smuts originally coined the term holism, and his ideas and theories appear to be used as a point of reference in almost all of the literature on this subject.

Both Smuts and the Gestalt theorists of the time saw a need to get beyond the reductionist approach of analysis that was carried over from the nineteenth century thinking. According to Ervin Laszlo (Lilienfield, 1978), reductionism is the passion for tracing complex phenomena or processes to their smallest parts. Anti-reductionist theorists suggested that it should be recognized that nature exhibits numerous instances of physical wholes in which parts are determined by the inner structure of the whole (Poynton, 1987). Even though Bullock and Stallybrass (1977) state that holism is hostile to analysis, the reductionist

approach was criticized by Smuts and his followers only in that analytical procedures were not sufficient, and that synthetic procedures were also necessary to understand nature.

With reference to the current usage of the term, Gribbon (Poynton 1987) stated that the term `holism' can be regarded as a modern buzzword with little shared understanding as to it's meaning. Nevertheless, he did feel that no other term was more apt in describing the quantum world than the word holism.

Holism is generally accepted as representing a process-orientated, hierarchical view of nature (Bullock & Stallybrass, 1977) which has subsequently been developed and translated into the systems theory approach (Poynton, 1987). This theory was an attempt to overcome the unicausal notion of aetiology and to unite biological and psychosocial variables in providing an understanding of nature (Harms & Lazarus, 1985).

## 4.3 GENERAL SYSTEMS THEORY

The concept of wholeness was developed into the general systems theory by Ludwig von Bertalanffy in the 1930's (Lilienfeld, 1978; von Bertalanffy, 1968). This was a direct response to the fragmentation of the scientific community into separate sub-disciplines (Vetere, 1987). Von Bertalanffy who was a biologist, Kenneth Boulding a trained economist and James Miller a physician-psychologist all contributed to the conceptual foundations of this theory (Janoski & Schwartz, 1985). The fact that these men came from different disciplines is not surprising when one considers that one of the primary aims of general systems theory was to provide an approach which would facilitate the unification of all science and nature (Bullock & Stallybrass, 1977; Robbins & Olivia, 1982). In fact Lilienfeld (1978) regarded the distinction between academically seperate fields as quite arbitrary from the systems point of view.

The word "system" has many interpretations depending on the context in which it is used (Wilson, 1984). This may have contributed to the confusion surrounding the understanding of general systems theory, the systems approach and systems theory. These terms appear to be used interchangeably and inconsistently. According to the Fontana Dictionary of Modern Thought (Bullock & Stallybrass, 1977), general systems theory is the same as systems approach and systems analysis. According to von Bertalanffy, general systems theory is the same as systems theory and the systems approach (von Bertalanffy, 1968). Both of these authors believed that systems theory strives to be a discipline of universal principles applying to systems in general irrespective of whether they are of a physical, biological or sociological nature. (von Bertalanffy, 1968; Bullock & Stallybrass, 1977).

General systems theory is an approach which views reality as an integrated hierarchy of organized matter and energy. It views all aspects of technical, human or natural life as organized systems which are interrelated, interdependent and which function as structured and bound units. The term `system' spans the physical, biological and social world and is concerned with organized complexity at the various levels. General systems theory attempts to provide a conceptual framework for understanding and explaining the `whole' and it's functioning, by examining the interdependence of it's parts in the widest variety of systems (Mesarovic & Takahara, 1975; Sutherland, 1975; Vetere, 1987). It could perhaps be argued that general systems theory was merely a philosophical approach and not a formed theory prior to the work of James Miller, who developed a theoretical framework in the 1950s.

Von Bertalanffy (1968) states that the roots of systems theory are complex and that the technological needs of World War II had a profound influence on it's development. Engineers were forced into working with systems of machines rather than single machines to develop complex equipment such as space vehicles or ballistic

missiles. This situation gave rise to the emergence of systems engineering methodologies. The methodologies were an attempt to integrate the effects of interactions between process units themselves, between the process being designed and other processes on which it was dependent. This meant that analysts were seeking to extend the boundaries of the systems being analysed so that they could encompass more of the whole (Lilienfeld, 1987; von Bertalanffy, 1968). At the turn of the century there was a parallel development taking place in biology where scientists started to study properties and behaviours of whole organisms. This idea of wholeness was central to von Bertalanffy's general systems theory where it was argued that the organismic thinking of the biologists could be applied to organised complexity in general (Lilienfeld, 1978; Sutherland, 1975).

General systems theory is based on the assumption that all systems are linked in a hierarchical relationship. The concept of hierarchy is regarded as a universal principal operating in all realms, i.e. physical systems, living species or social systems. Changes in one system is seen to affect change in others (Harms & Lazarus, 1985; Jaros & Cloete, 1987; Lilienfeld, 1978). These changes can occur because systems are able to receive input and provide output across system boundaries. System boundaries can be rigid or fluid, and by allowing or impairing the flow of information, can influence the relationship of the system to other systems as well as the dynamics of the system itself. Systems can have subsystems which are inferior or suprasystems, which are superior in relation to it in the hierarchy. In this context the terms inferior or superior does not mean that any level is `better', `more important' or has `more control' than another (Viney, Clarke & Benjamin, 1986). According to Sluzki (1983) general systems theories can be process oriented, structure oriented or world view oriented.

The general systems theory has been criticized on a number of counts for falling short of the need for an explanatory

model of the physical, biological and social world. Systems theory is usually applied on a level of abstraction, and although denied by von Bertalanffy (1968), has the danger of becoming increasingly general, diverse and vague (Berlinski 1976; Vetere 1987). Therefore the first major problem for general systems theory is to provide adequate descriptions of complex structures, even at the simplest level (Robbins & Olivia, 1982; Vetere, 1987). Secondly, little has been done to standardize the language components of general systems theory. Definitions are imprecise. Concepts are inconsistently used due to the absence of both rigorous definitions and a standard vocabulary (Robbins & Olivia, 1982; Sluzki, 1985; Vetere, 1987). Thirdly, being essentially an explanatory model, the main flaw in the theory lies in the lack of both adequate methods of analysis and methods of synthesis of systems (Vetere, 1987). The fourth difficulty is to some extent created by the former three in that the general systems theory is difficult to use because of it's complexity (Jaros & Cloete, 1987).

While Miller was the first, and according to Jaros and Cloete (1987) the only one, to construct a definite model for understanding living systems, his framework had a few problems. His framework was too complex, the levels of his theory too rigid and the process categories that he devised too great in number (Jaros and Cloete, 1987). Because of shortcomings and the need for a metatheory to facilitate discussion of general relationships within and between the various scientific disciplines (Vetere, 1987), Jaros and Cloete (1987) devised a simpler systems philosophy model called the Biomatrix theory.

## 4.4 THE BIOMATRIX THEORY

The Biomatrix is a theoretical framework which was developed in an attempt to improve on the existing frameworks of general systems theory. It attempts to improve on the models by being simpler, using clearly defined concepts and definitions and by extending the explanation of systems from a hierarchical viewpoint to a

process – based approach. The elements of dynamism, flexibility and processes within and between systems is a major departure from the traditional systems approach. Notwithstanding these innovations the Biomatrix theory is still a systems theory in that it approaches life in a holistic way. It strives to examine the overall pattern of processes between all living and lifeless things. This network of processes which constitutes life, is called the biomatrix (Jaros & Cloete, 1987; Jaros, Betts & Johnson, 1987).

According to Jaros, Betts & Cloete (1988), "the building blocks of matter are molecules, atoms and subatomic particles, namely material things. In the living world the emphasis falls on process, with material things playing a secondary role" (p1). This statement does not deny the importance of matter in living organisms but introduces a change of emphasis from matter to process. The essential role that matter plays in the occurrence of process is acknowledged in the biomatrix theory.

4.4.1 Historical development of the Biomatrix Theory:
The Biomatrix theory as it is today is the result of 20 years of evolving thought. Prof Gyorgy Jaros, the primary developer of the Biomatrix, is a biologist whose interest in the Biomatrix started due to his dissatisfaction with the traditional scientific approach to investigation. He felt that while it was important to look at individual entities it was essential to understand the whole first to obtain perspective.

The theory developed by shifting the focus of the systems approach from entities to wholes, by including the dualism of processes into their thinking and by labelling this as the doublet. (Reference: Personal Communication with Prof Jaros)

Anacreon Cloete worked with Prof Jaros on the Biomatrix Theory and they were both strongly influenced by Arthur Koestler and his ideas on the "holon". Koestler (Capra,

1987; Katakis & Thomassin, 1988) saw every organism as relatively autonomous while also being a part of a larger organism. He called the manifestation of independent properties of wholes and the dependent properties of parts a `holon'.

However it was felt that the "holon" was not quite ideal because it still placed emphasis on being part of things and things being part of us rather that on processes. They then became very interested in the work of Fritjof Capra and the following paragraph from his book The Turning Point explains very much what the Biomatrix Theory is:

> "The new vision of reality we have been talking about is based on awareness of the essential interrelatedness and interdependence of all phenomena - physical, biological, psychological, social and cultural. It transcends current disciplinary and conceptual or institutional boundaries, that would accommodate the formulation of the new paradigm, but the outlines of such a framework are already being shaped by many individuals, communities, and networks that are developing new ways of thinking and organizing themselves according to new principles. (Capra, 1987 p285)

John Betts began to work with Cloete and Jaros, and under the influence of Bateson's theories on structure and form, the concepts of structure, purpose and control were explored. It was discovered that these concepts were jointly the essence of process, and they called this the "teleon".

Currently the processes within the Biomatrix as well as the various applications of the Biomatrix Theory in the biological and social sciences are being explored .

4.4.2. Basic concepts of the Biomatrix:

4.4.2.1 HOLISM AND REDUCTIONISM: The Biomatrix theory is both contextual and analytical. This accommodates the positive value of both holism and reductionism. The

Biomatrix theory tends to be reductionist when viewing processes i.e. it breaks a system (doublet) down into smaller systems (subdoublets) to analyse the processes that are supporting the doublet. In the Biomatrix theory reductionism is of processes rather than things or structures. An example of this is the analysis of the development of cancer which can be better understood if the workings of subdoublets such as organs, tissues, cells, etc. are examined. However, when applying the Biomatrix framework holism is always stressed. This holds even when using reductionism as it is used with the purpose of achieving a better understanding of the whole (Jaros, Betts & Johnson 1987).

The Biomatrix framework has been developed to approach life and the components of life in an entirely holistic way. By it's very nature, the Biomatrix theory accepts and accommodates the synthetic and dynamic forces of life. It regards matter, energy and information (MEI) as inseparable in the process of life, and postulates that the relative interaction of these variables in a given system determines the structure of that system.

The Biomatrix Theory has its core in the living hierarchy as suggested by the general systems theory as we know it today. It also includes lifeless, natural and man-made things which are seen to be locked into a complex network of processes. It expresses the fundamental unity between these three entities and the rest of nature. This approach is consistent with the concept of holism as Smuts presented them in his writings (Jaros & Cloete, 1987).

4.4.2.2 TELEON: The term teleon is derived from the Greek word teleos, meaning aim or goal. According to the biomatrix theory teleon can be defined as "a controlled structure-process entity that has a specific well definable purpose" (Jaros, Betts & Johnson 1988 p10). In fact life can be conceived as a complex arrangement of teleons.

The teleon, or processes in the biomatrix, is a series of

controlled and interrelated events and can exist because of internal or externally acquired purpose. Purpose means that a system has a goal and is organised for that purpose (Jaros, Betts & Cloete, 1988). Katakis (1988) also suggests in his 'theory of living systems' that purposiveness and self-directedness are basic properties of living systems. Like Jaros et al., Katakis differentiates between purpose and goals. He states that purpose refers to subjective aim or intent as a phenomenom of nature, while goals refer to the system's interaction with its environment.

Besides purpose, the structure of the process is very important. This process structure can be comprised of any one or more of the properties of matter, energy or information. A further point about the processes of life is that they all have inbuilt governance or control. Governance is important in that it requires that the processes must be organised and regulated in their activities to ensure that their purpose is fulfilled. Therefore purpose, structure, process and governance are inseparable, and with time, are capable of merging to form a "complex process system" called a teleon. An example of this would be the riding of a bicycle which at first is a deliberate process which with time and experience becomes part of our physical and mental nature i.e. a complex process system (Jaros, Betts & Cloete 1988).

4.4.2.3 CONCENTRIC HIERARCHY: There is one gross pattern in the Biomatrix. This pattern is a complex arrangement of teleons, which are in relative balance to form doublets which are in turn arranged in the form of a multilayered concentric (Chinese-box) hierarchy. Wholes of increasing complexity enclose one another and this illustrates the dual nature and unity of wholes. The biomatrix contains not only living entities but also non-living things which can be an integral part of a living system eg. food, utensils, a house etc. can be part of the family system. This means that entities are found within other entities. For example, families are made up of people which are made

up of organs, then cells, then molecules and then atoms. While each successive entity contains smaller entities being `higher' or `lower' in the hierarchy does not mean being more or less important. Besides providing a good explanation of the structure of teleons within the biomatrix, the Chinese-box idea also facilitates the concept of `radial' movement within the matrix (Jaros, Betts & Cloete 1988; Jaros & Cloete 1987). These ideas are consistent with those of Capra (1987), although he regards the term `hierarchical' as misleading because it is generally used to refer to authoritarian structures. He uses the term `stratified order' to refer to what he calls "multileveled patterns of organization characterized by many intricate and nonlinear pathways along which signals of information and transaction propagate between all levels, ascending as well as descending" (Capra, 1987 p304-5).

4.4.2.4 ENDO- AND EXODYNAMIC PROCESSES: The main processes in the biomatrix take place either toward the interior or toward the exterior of the "Chinese-box" hierarchy. There are two types of processes in the biomatrix, namely endodynamic and exodynamic processes. In a system teleons can be either endo- or exodynamic depending on their purpose. Endoteleons have their purpose directed toward a subsystem while exoteleons have their purpose directed toward a suprasystem (Jaros & Cloete 1987; Jaros, Betts & Cloete 1988; Jaros, Betts & Johnson, 1987). For example, the purpose of sport and recreation in society is directed towards its members and is therefore an endodynamic process. Conversely, the giving of charitable works during time of community need is directed towards the response of society. The community level is outside of the level of the individual and therefore charitable works is an exodynamic process

Von Bertalanffy, in his book on general systems theory (1968) mentions the term dynamic teleology which is quite different from the processes of the teleon. He defined teleology as the directivity of processes and he believed that directivity was dependant on structure. While these

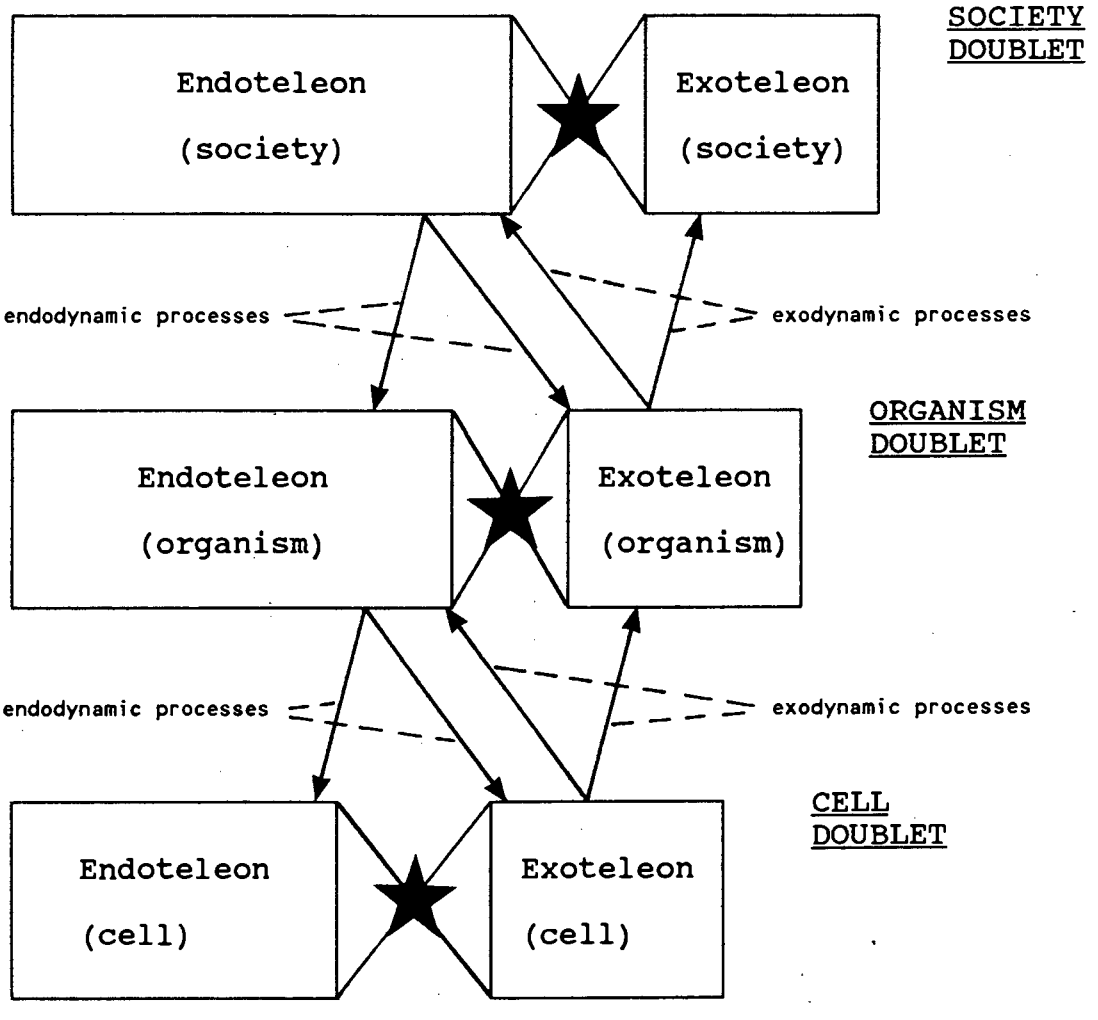
two terms sound quite similar they should not be confused as their meanings are very different. Von Bertalanffy's teleology refers to a foreward looking philosophical position, while Jaros et al.'s teleon and teleology are terms which explain concepts in the Biomatrix Theory.

4.4.2.5 DOUBLETS: Jaros and Cloete (1987 p222) state that "while nature can be considered to be an invisible whole, there are parts of it which could be regarded as wholes themselves." These wholes have been referred to by previous researchers as "holons", "centers" or "foci" but Jaros and Cloete refer to them as doublets (Jaros & Cloete 1987).

A doublet is a process which occurs when an endoteleon and an exoteleon are in relative balance. A doublet is comprised of endoteleons and exoteleons which are concentrated in two imaginary poles. One pole is directed towards suprasystems (exo), and the other towards subsystems (endo). These exo- and endoteleons represent the self-assertive and the integrative processes of the doublet. Interactions between processes takes place mainly within the poles of the doublet. Interaction outside these regions is possible, thereby creating a duality of nature as well as a unity of the doublet (Jaros & Cloete. 1987). See Figure 1 for a diagrammatic representation of these processes which illustrates the cyclical nature of the matrix of doublets. The Chinese-box hierarchy is also illustrated by the complex way in which the doublets are able to interact with one another.

4.4.2.6 ENTROPY AND TELENTROPY: According to the Oxford dictionary (Fowler and Fowler, 1986) entropy is the measure of the unavailability of a system's thermal energy for conversion into mechanical work. Even though this is a physical concept, translated into the new term `telentropy' it is useful in explaining the dynamics of teleons. Telentropy is entropy in a teleon or in a process. The difference between them is that entropy can apply to

Figure 1: A schematic representation of three subsequent doublets. Note the dual nature of the doublets, i.e. how processes can occur from supra-systems to sub-systems, or from sub-systems in the direction of supra-systems. Endodynamic processes are in the direction of subdoublets while exodynamic processes are in the direction of supradoublets. Processes can take place at a variety of levels between a wide variety of doublets. Each doublet is capable of generating and receiving both endo- and exodynamic processes demonstrating the dynamic complexity of life. (Adapted with permission from Jaros & Cloete, 1987)



systems whether they have a purpose or not, but telentropy can only apply to purposeful systems. Essentially entropy is related to disorder. When order is created one calls it negative entropy or syntropy. When a teleon is created an ordered structure comes into being, and entropy is reduced.

Entropy can be converted into telentropy and vice versa. Even though entropy increases constantly with all change,an increase in telentropy does not necessarily follow. For example when we exercise we are continuously burning up ingested fuel (i.e. food), and thus entropy passes into the environment as heat and energy. When we have to buy food to replace our energy loss this may change back into telentropy if we are short of money. However if we have a steady income and money for food is not a problem, then telentropy will not occur. In fact the closer we get to our goal, the greater the chances of reaching it and less telentropy results. This suggests that telentropy has a lot to do with efficiency.

When dealing with a more closed system such as a scientific concept such as a mathematical equation, one can be more certain about the predictability of success. However, it is thought that there are very few true closed systems. With an open system it is more difficult to measure or predict efficiency. This can be illustrated by the example of travelling in a car to a destination. Efficiency is the property of the car while telentropy is created by factors outside the mechanical systems of the car. These factors can include other cars, traffic lights and the attitude of other drivers. Efficiency is a mathematical concept whereas telentropy is a statistical, probabilistic one (Jaros, Betts & Cloete 1988).

Telentropy can be injected into a teleon through the changing of goal, structure, energy, matter and information flow or governance while the teleon is in action. Teleons have limits as to the amount and duration of stress that they can manage without considerably increasing their

telentropy. The big problem with the transfer of telentropy is that it comes back to the originator of the telentropy sooner or later. An example of this is when one is stressed and then does things in a hurry. One tends to make mistakes and then at a later stage have to either take responsibility for the errors or spend more time redoing the task properly, generating more stress. The art of preventing telentropy coming back to the source is by transferring it out of the system in the form of entropy that can be dissipated for example by prayer, exercise, laughter etc. (Jaros, Betts & Cloete 1988).

4.4.3 How the Biomatrix Theory works: The Biomatrix contributes to our understanding of life by providing an analytic and synthetic conceptual framework that we can apply to processes that we want to investigate. To understand how the Biomatrix theoretical framework is applied, the analogy of a net can be used. The elements of the net which are important are the knots and the strands of rope that link them. In this analogy the impression of a net is provided by arrangement of doublets and teleons in a conceptual space. The doublets are the knots and teleons are the interconnecting ropes of the net. The strands of rope represent the processes in the matrix while the knots represent entities. This net is arranged in a Chinese-box hierarchical way in which doublets range in opposite directions from subatomic particles to the whole universe (Jaros, Betts & Johnson 1987).

An example of how an entity fits into the multilayered concentric hierarchy is the way that an individual experiences life processes. The individual can be seen as a knot in the net analogy, and the strands of rope represents his/her connection to other entities. These entities may for example be other family members, the biological components of the body, emotions, employment, health care system, politics or religion. While the individual in our example is connected via teleons with all of these entities (doublets), it must be remembered that

they are structured around the individual in a multilayered concentric Chinese-box hierarchy. For example the health care system would be a supradoublet to the family, which would be a supradoublet to the individual, which would in turn encompass the biological components which are a subdoublet. The religious supradoublet, should it differ from the family's viewpoint, would be a supradoublet sharing processes (or a teleon) directly with the individual. Should the family perhaps actively disapprove of the individual's religion, it may then share the religious supradoublet but via a different strand of rope i.e. the nature of the family's interaction with religion would be different to the individual's.

Jaros, Betts & Cloete (1988) suggest that one can think of the strands of rope as teleons in the matrix. They say that teleons are single conduits through which matter, energy or information can pass for the benefit of either the upper (outer) or lower (inner) level. Teleons can start anywhere in the hierarchy and pass through any number of levels forming links between doublets as in our net analogy.

4.4.3.1 ADAPTATION IN THE BIOMATRIX: Doublets are regions or systems in the biomatrix where the exo- and endoteleons are (or should be) in balance. The endodynamic processes use up the biomatrix's resources by increasing entropy, while the exodynamic processes provide a balance by producing organisation. Contrary to general systems theory where homeostasis is emphasized as the ideal state for a system, it is not regarded in this way in the Biomatrix theory. While homeostasis is an essential part of this theory it is not always desirable, or even possible. Controllable stress is regarded as very important for growth and evolution to take place in complex dynamic systems. In the normal course of events stress will arise to threaten all systems, and the extent to which the system can adapt and stabilize itself will determine how healthy the system is. Systems can respond to negative feedback by means of the 'adaptive

self-stabilazion' (Laszo 1983) function of the endodynamic processes. However if the feedback to the system is positive, exodynamic processes are activated to achieve Laszlo's (1983) 'adaptive self-organization'. It can be said that stress situations are important in that they initiate new creative processes which provide solutions to problems (Jaros & Cloete, 1987).

4.4.3.2 TRANSFER OF TELENTROPY INTO A TELEON: According to Jaros, Betts and Cloete (1988), to manage stress effectively we should organize our lives for the minimum telentropy transfer between teleons. As was previously mentioned, telentropy can be transferred into a teleon through interference with purpose, structure, MEI flow or governance. Interference with purpose or goal can occur in three ways. Firstly because of mismatch between purpose and goal. An example is when a cancer patient in Groote Schuur hospital needs support from their spouse but the spouse is at home in Kenhardt. The chance of reaching the goal of receiving support from the spouse is very low, i.e. the telentropy of the system will be high. A second way to create telentropy is by shifting the goal while the teleon is in action. An example of this is when one sets out to meet a deadline and someone changes the deadline halfway through the task, i.e. brings the deadline forward. The third and probably the worst situation is when the goal is not clear or does not exist at all in which case the teleon has a very high level of telentropy. An example of this is when a patient is diagnosed as having cancer and even though the doctors recommend treatment they are unable to say what the patients prognosis is or if the treatment is likely to be effective. This means that the patient has vague or unrealistic goals, or stumbles on without a goal at all (Jaros, Betts & Cloete, 1988). Katakis (1988 p3) also regards this point as important, and says that "systems that have confused, contradictory or vague purpose are bound to manifest symptoms of malfunctioning".

Interference with structure can produce high telentropic

states if teleonomic flexibility is low (i.e. if there is no redundance in the system). If there are several alternative routes to get to a certain goal then telentropy will stay low. However, if there is only one route and it is blocked then telentropy will be high. An example of this is the income process. This process consists of going to work, being productive and receiving income. The structure of the system is being strong and well enough to work, having a place to work at and being productive. If a person becomes too ill to work but has alternative resources such as insurance, savings or sick leave telentropy will stay low. However if the person has no resources with little prospect of being able to return to work telentropy will be very high in the income teleon (Jaros Betts & Cloete, 1988).

The easiest way to transfer telentropy into a teleon is by interfering with the flow of matter, energy and information (MEI). This can be done by interfering with the process or governance. The process and governance are generally less stable than the purpose and the structure of the teleon (Jaros Betts & Cloete 1988). An example of this is when a person develops lung cancer by smoking too much, exercising too little and having a genetic disposition towards cancer. The first two reasons have to do with matter and energy flow and the latter with information flow and governance, which are closely connected (Jaros Betts & Cloete, 1988). Smoking is transferring matter into the system while exercise can balance some of the matter entering the system by strengthening the respiratory system, if the exercise is insufficient the person will not have healthy lungs. A problem with the governance, such as genetic predisposition to cancer, is that lung cells will perhaps still be inclined to uncontrolled growth even if the person does not smoke.

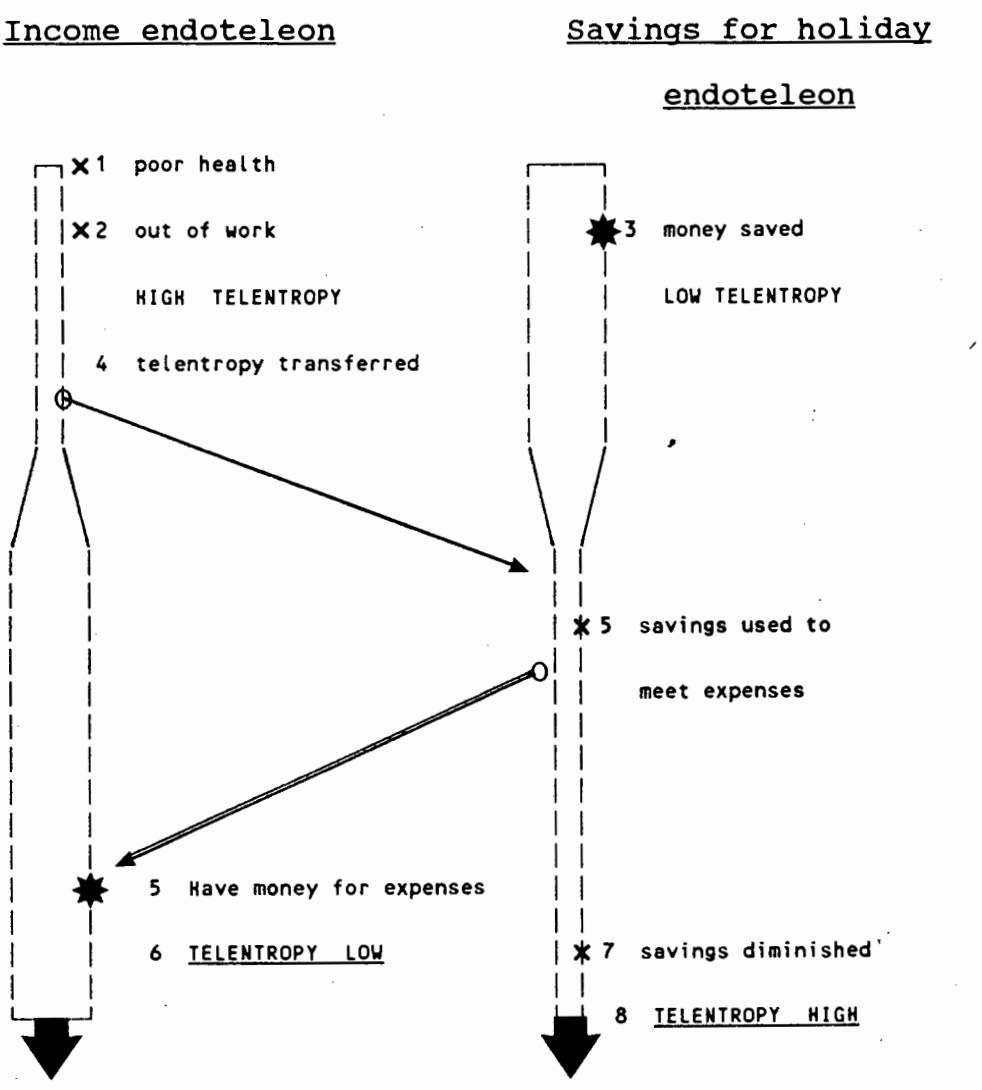
The flow of telentropy is closely linked to the structure of the teleons within the endo- and exopoles of the doublet. Teleons within an endopole of a doublet are closely linked to one another. In the exopole they relate

more closely to one another and less closely to endoteleons. There is contact between teleons in the exopole of the doublet in the same way that teleons in the endopole relate. The more self-contained the teleon is, the greater the chance that the teleon's goal will be achieved under all circumstances. Effectively this means minimizing all environmental influences on the teleon. However, if there is a breakdown within the teleon in a living matrix, the subdoublets (i.e. components of the doublet) can be left without the matter, energy and information that the teleon is meant to supply.(Jaros, Betts and Cloete (1988) According to Jaros, Betts and Cloete (1988), in biological and man-made systems the interconnections between teleons within the poles provide greater flexibility to the doublet. An example of this is when a person cannot earn money due to ill health. He can borrow money from his holiday savings to get by for the time being. This will mean that the teleon from which the money was borrowed will probably find it more difficult to reach its goal, i.e. telentropy has been transferred to it because the holiday money will be eroded. (see Figure 2)

4.4.3.3 APPLYING THE BIOMATRIX FRAMEWORK: The following steps were detailed by Jaros, Betts and Johnson (1987) and explain how one can use the Biomatrix theory to understand physical, technical and human situations:

1 Define the system (doublet) being investigated e.g cell, person, work situation, health care system.
2 Determine the subdoublets which surround the process being investigated e.g the subdoublets of a person are organs such as eyes, systems such as the circulatory system, non living things such as clothes jewelry etc.
3 Determine the supradoublets which surround the doublet. The supradoublets of a person may be the family, work, sport and church.
4 Determine the needs of the subdoublets as well as their importance within the doublet.
5 Determine the needs of the supradoublets and their relative importance.
6 Determine which supradoublet provides for the

Figure 2: Diagram demonstrating the transfer of telentropy between teleons. (1) If an individual is ill and (2) not able to work and yet has expenses to meet, high emotional stress and therefore high telentropy in the income teleon will be experienced. However, (3) if there are savings available (4) telentropy can be transferred and the money saved can be (5) used to meet living and medical expenses. This (6) reduces telentropy in the income teleon because the chance of this teleon reaching it's goal is high. (7) Due to the diminishing of the savings in the holiday teleon, the probability of it reaching it's goal has been reduced and (8) telentropy is therefore high.



fulfillment of the needs of the doublet. This can give an indication of paths through which telentropy can be transferred into the doublet from the environment.

7 Identify the teleons within the doublet and see how well they are regulated.

8 Identify connections between the teleons through which telentropy can be transferred.

These steps can be illustrated by the following simple example:

1 The doublet to be examined is a cancer patient's pain control medication.

2 The subdoublet is; chemical composition of the medication.

3 The supradoublets are; the medicine container, instructions for ingestion.

4 The needs of the subdoublet is; to be kept cool and dry.

5 The needs of the supradoublets are; the medicine container - a safe place to stand, instructions for ingestion - to be clearly stated and easily understood. In terms of importance the instructions for ingestion's needs are seen to be most important as accurate dosage and frequency are essential for effective pain control.

6 Fulfillment of the needs of the doublet; the instructions for ingestion provides for the needs of the doublet by providing the correct dose and frequency for the medication to be effective.

7 Regulation (governance) of teleons; if the dose suggested is too small or too large, taken too frequently or too seldom the medication will not be optimally effective. In other words it is important that teleons occur in the optimal ammount and frequency to fulfill the needs of the doublts.

8 Possible transfer of telentropy; if the medication is not kept dry, or kept in a safe place, then the medication could be spoilt or accidently taken by a child and will therefore be unavailable to the

patient. In this instance the probability that the doublet will reach it's goal (receiving medication) will be reduced, and therefore telentropy in the patient's pain control teleon will be increased.

By following these steps we can apply the Biomatrix theory and attempt to understand the needs, problems and psycholgical stress of cancer patients.

## 4.5 CHAPTER SUMMARY

The development of systems theory and subsequently general systems theory from that of holism, was a major step in ending the dominance of the reductionistic world view which dominated scientific thought during the last three centuries. Because of the shortcomings of general systems theory, the biomatrix framework was developed to meet the needs of the scientific community for a simple, practical and holistic approach to understanding all aspects of life. The essence of the biomatrix framework is the presence of doublets comprised of various organizational complexity. Generally more complex doublets tend to enclose the less complex ones but doublets can also exist side by side. Doublets are comprised of teleons which are directed in two opposite radial directions of the living hierarchy and have duality of purpose. This duality of purpose provides the basis for the analysis of life using the biomatrix. The biomatrix focuses on processes within their contextual environment, thereby providing a full understanding of them (Jaros & Cloete 1987).

# CHAPTER 5: METHODOLOGY

## 5.1 CHAPTER INTRODUCTION

In this chapter the methodology of this study will be detailed. A brief summary of the pilot study will be provided as well as information on the collection of data, subjects and the questionnaires used. Methodological details will be provided for both the the rural sample of cancer patients as well as for the urban control group of cancer patients.

## 5.2 PILOT STUDY

The fieldwork of this study covered an extensive geographical area and involved the time and commitment of many volunteers and cancer patients alike. A pilot study was undertaken in the Paarl magisterial district to investigate the viability of the proposed method of information gathering, the effect of interviewer bias, the language and content of the questionnaire and problems that the interviewers may have encountered (Stopher, Meyburg & Arnim, 1979). The Paarl magisterial district was chosen because it was situated close enough to Cape Town to enable the survey co-ordinator to control the pilot study directly, and because farming activities dominated most of the district making it 'rural' enough to constitute a good pilot study area.

The pilot study sample consisted of 29 cancer patients. The proposed method of information gathering proved to be practical and simple, and good co-operation was received from the local health care resources. From time that interviewers needed to trace patients and interview them, it was estimated that one interviewer had to be recruited for approximately six to eight patients.

After control interviews were done using multiple interviews and multiple respondents, it appeared that these factors introduced very little bias into the interpretation or completion of the questionnaire. On the basis of the

results of the pilot study, the questionnaire proved to be easy to understand and simple to complete.

## 5.3 SAMPLING PROCEDURE

5.3.1 Rural Sample: The population being investigated was located in a geographically defined area. This area was 36 magisterial districts and covered almost the entire rural region of the Western Cape (see Figure 3).

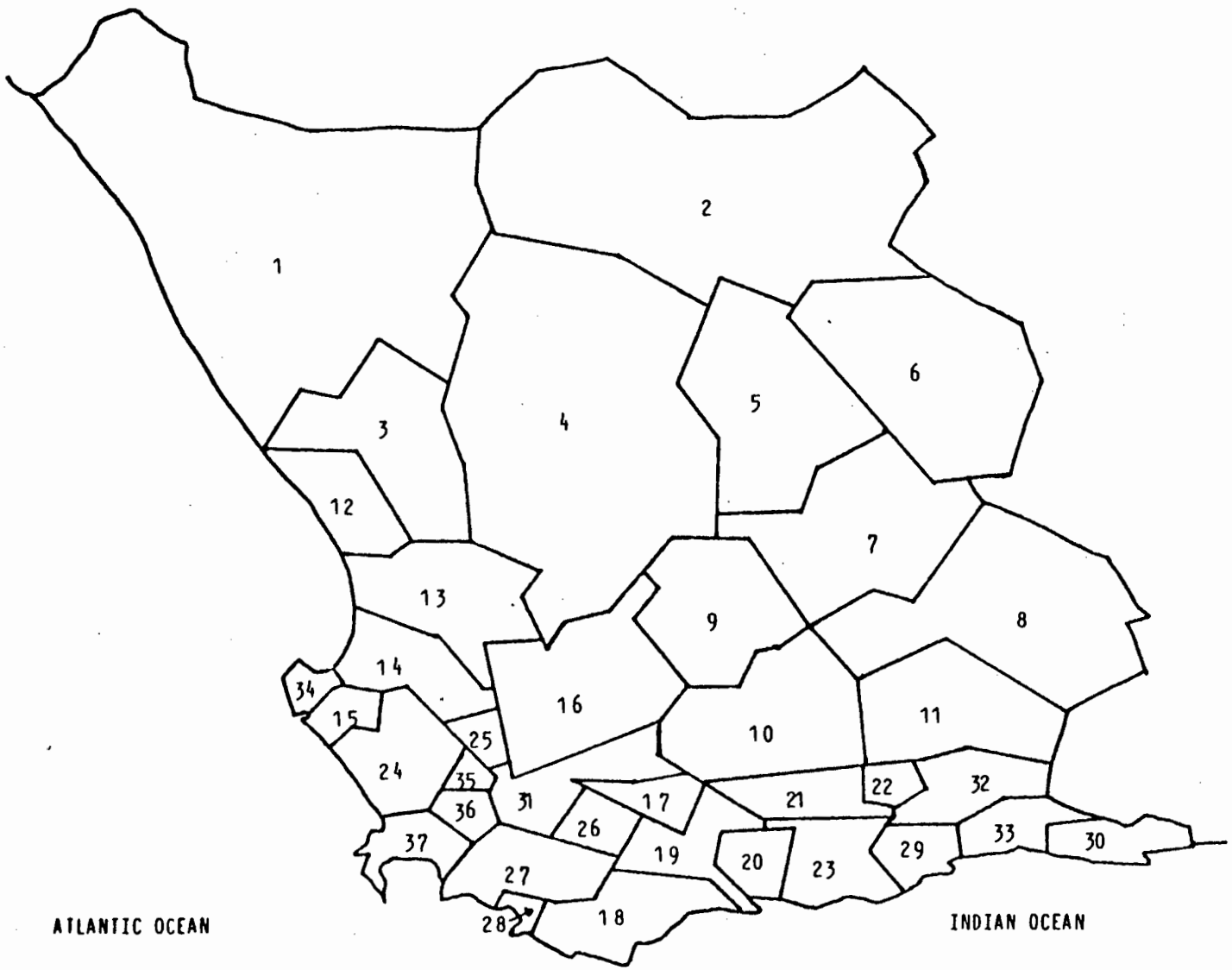
The information on the incidence and prevelance of cancer in South Africa is very limited and unreliable, making it impossible to obtain a random sample of cancer patients for this study (Bradshaw & Harrington, 1985; Editorial, 1983; Wyndham, 1985). In an attempt to obtain a representative sample, magisterial districts were randomly sampled from the area being investigated and then all the known cancer patients who were resident in these districts constituted the sample of subjects.

To ensure that sparsely as well as densely populated magisterial districts were evenly represented in the final sample, an attempt was made to stratify the districts into homogeneous strata. The population density of each district as well as Beaton and Bourne's (1980) urban hierarchy of towns were used to stratify the districts. Beaton and Bourne's urban hierarchy was compiled by classifying areas of South Africa into hierarchies according to their size and the distribution of various services and institutions in the locality. These criteria were used for stratification because the population, area size and size of main towns influence the availability of health care services in each district. In many instances it reflects the distance from cancer treatment centres (see Figure 4).

Each district represented a cluster of patients within a stratum. The effects of cluster and stratified random sampling had to be considered and an adequate sample size had to be achieved (Fleiss, 1981). The following districts were sampled from the strata using random

# FIGURE 3

## POPULATION OF MAGISTERIAL DISTRICTS




1 Namaqualand
2 Kenhardt
3 Vanrhynsdorp
4 Calvinia
5 Willlston
6 Carnarvon
7 Fraserburg
8 Beaufort West
9 Sutherland
10 Laingsburg
11 Prince Albert

12 Vredendal
13 Clanwilliam
14 Piketberg
15 Hopefield
16 Ceres
17 Montagu
18 Bredasdorp
19 Swellendam
20 Heidelberg
21 Ladismith
22 Calitzdorp
23 Riversdale

24 Malmesbury
25 Tulbagh
26 Robertson
27 Caledon
28 Hermanus
29 Mossel Bay
30 Knysna

31 Worcester
32 Oudtshoorn
33 George

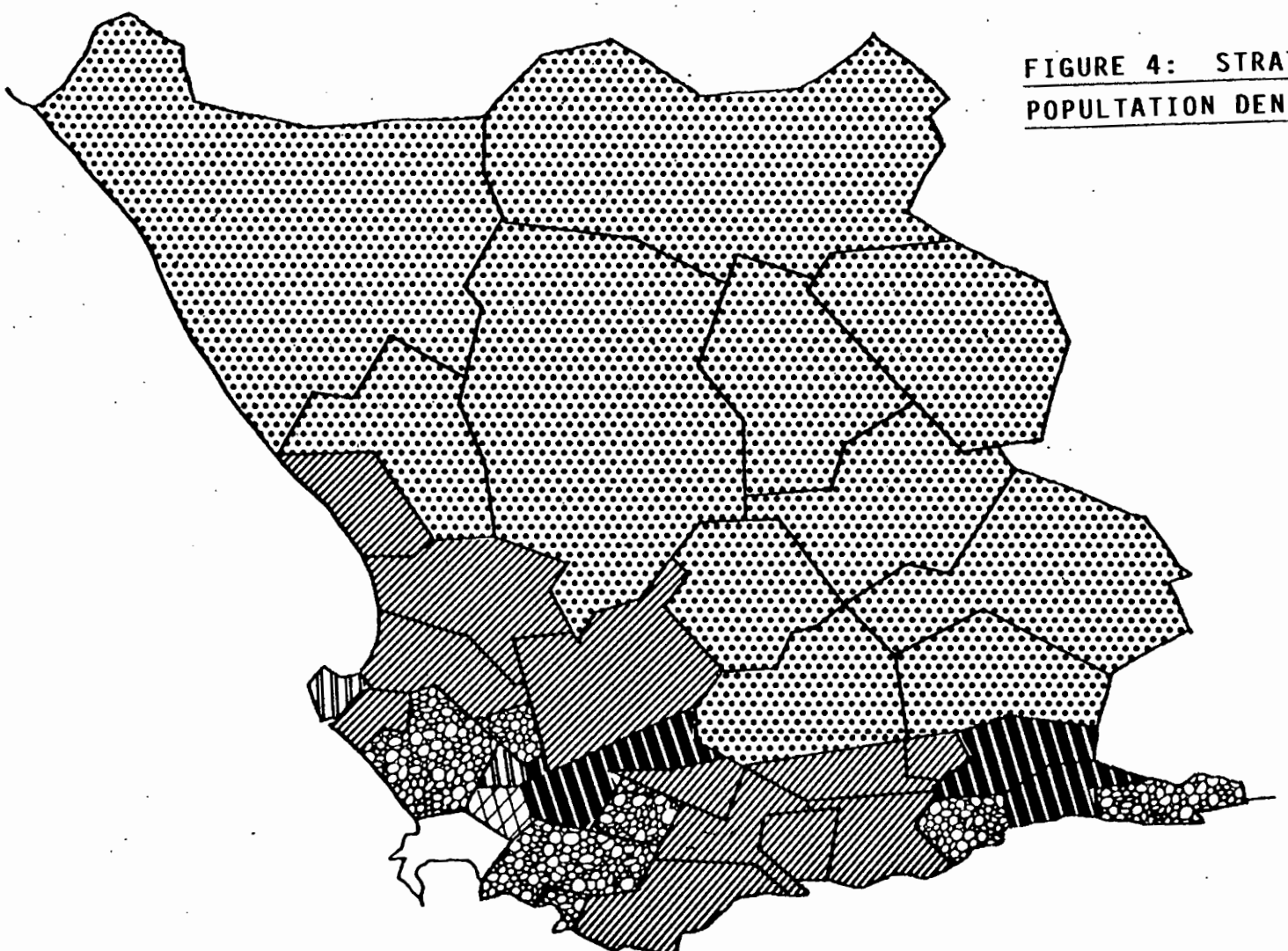
34 Vredenburg/Saldanha
35 Wellington

36 Paarl

37 Metropolitan areas of Cape Town

Comprises 7 magisterial districts

FIGURE 4: STRATIFICATION OF SAMPLE BY POPULTATION DENSITY



STRATA 1 TO 5

People per km²

1 0,3 - 1,7

2 16,1 - 25,7 (With major hospital)

3 3,2 - 7,3

4 42,6 - 100,8

5 16,1 - 25,7

Pilot Study

sampling techniques: (see Figure 5)

Stratum 1; Kenhardt, Frazerburg, Calvinia, Carnarvon Prince Albert, Vanrhynsdorp (6 out of 11 strata)

Stratum 2; Clanwilliam, Ceres, Riversdale, Calitzdorp, Hopefield, Vredendal, Montagu (7 out of 12 strata)

Stratum 3; Robertson, Mossel Bay, Hermanus, Tulbagh (4 out of 7 strata)

Stratum 4; Oudtshoorn, George (2 out of 3 strata)

Stratum 5; Vredenburg/Saldanha (1 out of 2 strata)

Stratum 6; Paarl (Pilot Study)

Cancer is badly under reported (Bradshaw & Harrington, 1985), and mortality estimates for the districts sampled had to be obtained from the Medical Research Council data bank for the years 1979, 1980 & 1981. Confidence intervals were calculated at the 95% confidence level to estimate the prevalence of cancer patients in each magisterial district. Since the stratified random sampling technique (Fleiss, 1981) was used without knowing the population size of cancer patients, estimates of patients were made according to the size of the strata. When these approximations were considered together with the actual population numbers in the various areas, very small statistical adjustments were made (Levy & Lemishow, 1980). Based on this estimate, the minimum number of patients to be interviewed in each area was stipulated and the target sample size that was to be obtained from the 21 districts was set at 509 patients.

After the data on the rural cancer patients had been collected and analysed, it became clear that there were no real differences for strata 1,2 and 3 between the demographic information on the patients or between the needs, problems or stress that they reported. These three strata were combined and called the sparse stratum, stratum 5 was called the minor stratum and stratum 4 the major stratum. (see Figure 6)

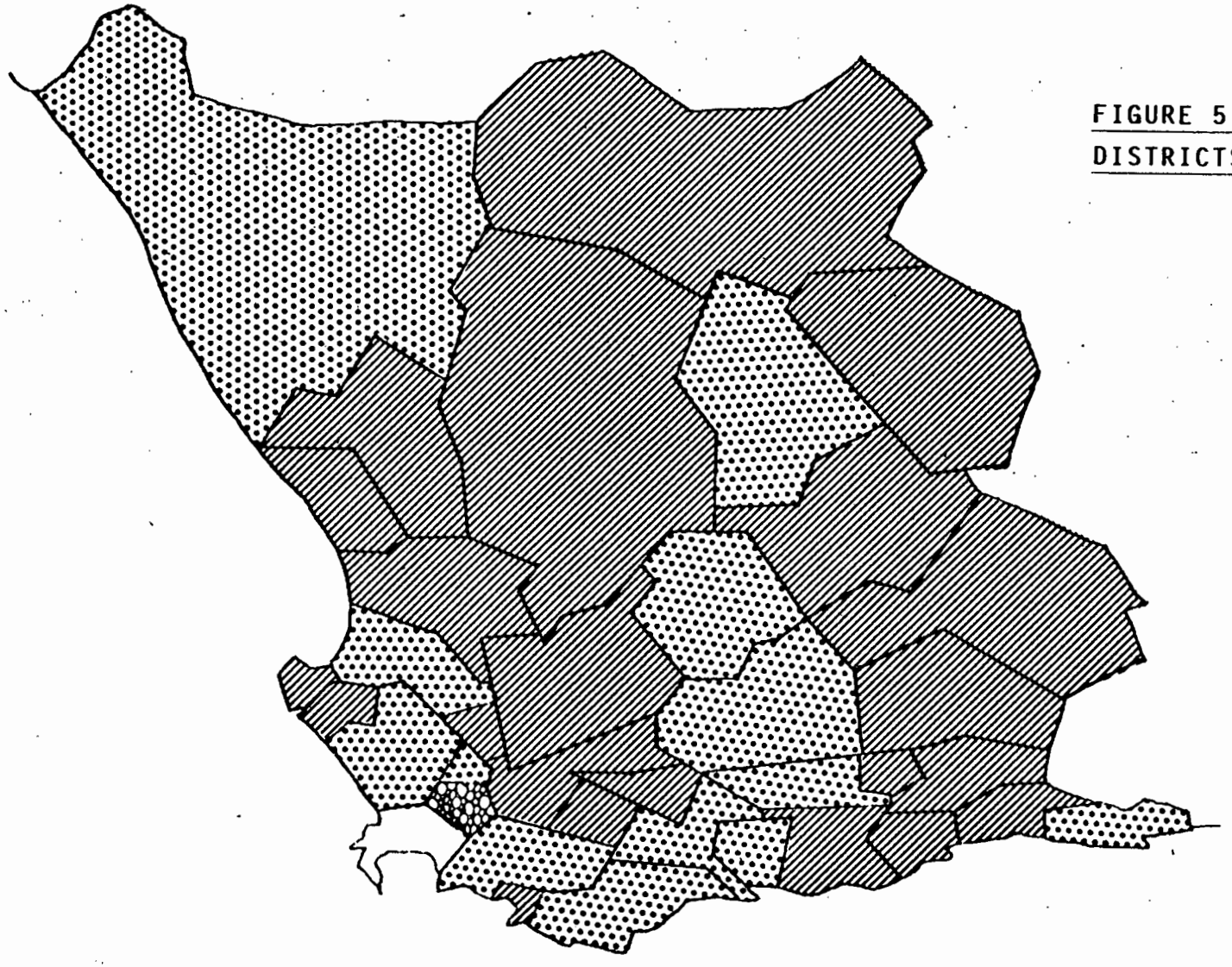


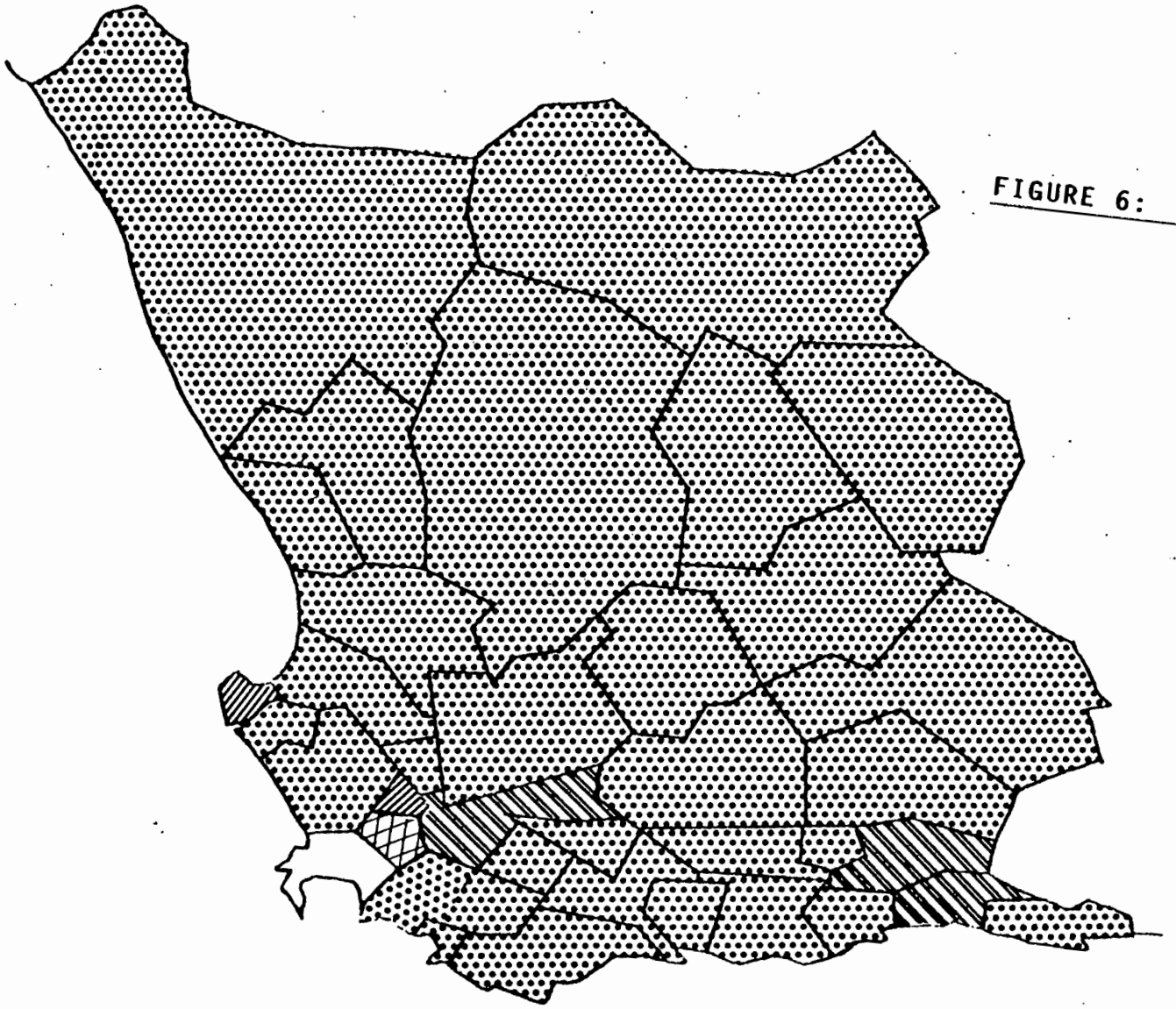
FIGURE 5: MAGISTERIAL DISTRICTS SAMPLED (N = 21)

Sampled

Not Sampled

Pilot Study

FIGURE 6: REVISION OF STRATA



Pilot Study

STRATA :

SPARSE

POPULATION DENSITY :

0,3 - 25,7 people per km²

MAJOR

16,1 - 25,7 people per km²

MINOR

5.3.2 Urban Sample (Control Group): While a random sample of urban cancer patients or a normal distribution sample of a South African population would have constituted the ideal control group for this study, this was not practical. In an attempt to have an urban control group that represented a diversity of race, sex and age, a minimum of 40 cancer patients in each of the racial categories of white, coloured and black had to be interviewed. The categories were further sub-divided for an even distribution of sex and age. As no statistically calculated minimum sample sizes would have been practically within the limits of this study, these minimum sample numbers were based on the opinion of two statisticians. They suggested that the minimum numbers proposed would provide a reasonable estimate of median stress scores in the urban cancer patient population (Dr Debbie Bradshaw and Dr Hannes Botha, Medical Research Council of South Africa).

Patients who attended the oncology out-patient section or the oncology ward at Karl Bremmer Hospital, or who were attended to by National Cancer Association social workers or nurses were interviewed. A sufficient number of patients were interviewed until the minimum number of patients in each category was obtained. Where possible more than the minimum number of patients in each sub-category were interviewed.

## 5.4 DATA COLLECTION PROCEDURE

5.4.1 Rural Sample: The survey co-ordinator recruited a fieldwork co-ordinator in every magisterial district that was sampled to control the collection of data in that district. A list of all the cancer patients living in the district was then compiled using every availabe resource such as doctors, clinics, small hospitals etc. The fieldwork co-ordinator in each magisterial district was asked to recruit interviewers to trace the patients to complete the questionnaire. On the basis of information obtained from the pilot study they were advised to recruit one interviewer for every six to eight patients. Even though the questionnaire was relatively simple it was decided to use trained volunteers to interview the

patients. The interviewers used the questionnaire as an interview schedule to accommodate frail, illiterate or uneducated patients and to standardize the interview procedure. Every effort was made to recruit social workers, nurses, doctors or other volunteers with interviewing skills to do the necessary interviewing.

The training of the fieldworkers entailed providing basic background information about the study, guidelines regarding the administration of the questionnaires and instructions for the handling of the completed questionnaires as strictly confidential. An appropriate time limit was set for the fieldwork to be undertaken in each district. This was three to four months depending on the number of patients who had to be traced. The local fieldwork co-ordinator was asked to monitor all the interviews, collect the completed questionnaires and liaise closely with the survey co-ordinator.

The survey co-ordinator played a major role in motivating and training fieldworkers, conducting control interviews, ensuring that the necessary control of confidential material was maintained and in collecting the completed questionnaires from the 20 districts.

5.4.2 Urban Sample (Control Group): Social workers and nurses from the oncology departments of Karl Bremer Hospital interviewed patients who lived in the Cape Town area and who attended the oncology clinics or stayed in the oncology wards. National Cancer Association social workers and nurses interviewed all the Cape Town patients with whom they came into contact until the required minimum number in the various catagories was obtained. These patients came from many different hospitals in Cape Town, both private and provincial institutions. This provided a broad cross section of the urban patient population.

5.4.3 Health Care Resources for Rural Cancer Patients: As part of this research project and to complete the thorough investigation of rural cancer patients, data was

gathered from 161 rural based health care professionals who offered a wide variety of medical, practical and supportive services to local cancer patients. While this information was important in achieving a broader understanding of rural cancer patients in their contextual environment, it was not within the parameters of this dissertation to include this data.

## 5.5 SUBJECTS

### 5.5.1 Rural Sample:

RACIAL DISTRIBUTION: (Author's note: For this sections patients were classified according to the "so-called" white, coloured and black population groups. While these classifications may not be desirable they were deemed necessary as race may well have been correlated with socio-economic conditions and in turn influence the experience of being a rural cancer patient in the South African context. (Braddock, Crain, McPartland & Dawkins, 1985; Fosser, 1986; Greenberg, 1984; Lewis, 1985)

Of the 496 patients who were interviewed 282 were `white', 200 were `coloured' and 14 were `black' (see Figure 7). The numbers of `white' and `coloured' patients were not consistent with the racial distribution of the general population for these areas (S.A. Census, 1980) where figures for `coloureds' (70%) were much higher in all areas than for `whites' (22%). The small presentation of `blacks' (8%) was consistent with the distribution in the normal population (SA Census,1980) where with the exception of the major strata, very few blacks were resident in the areas being studied. Because of their very small number, `black' patients were excluded from the analysis of data which provided generalised information on rural patients of the Western Cape as a population. However, they were included for all comparative analysis with the urban control group because an acceptable number of urban `black' cancer patients were interviewed. Their data was also included for the analysis of emotional needs of patients because this was seen to be an individual rather than a demographically related issue.

Racial distribution appeared to be similar for most areas with the exception that the major stratum showed a disproportionately high number of `white' subjects and very few `coloureds' (Figure 7). This difference is not consistent with the census population figures for these districts. This may be because whites were easier to trace and also because some `coloured' residential areas were regarded as unsafe for interviewers to trace patients due to political unrest which occured concurrently with the fieldwork of the survey. In the minor stratum no `black' patients were interviewed and 80% of the subjects were `coloured'. This is a reflection of the racial distribution for the areas as reported in the population census.

For the major stratum caution must therefore be exercised when interpreting problems reported by patients. Race may well be confounded with socio-economic status and therefore problems will be representative of the predominantly white samples and not of most of the cancer patients living in the area.

AGE DISTRIBUTION: Of the 482 patients interviewed 37% were 65 years of age or older, 25% were between the ages of 55 and 64, 32% were between 35 and 54, and 6% were 35 or younger. Although 62% of patients were over 55 years of age, this was found to be consistent in all areas (see Figure 8) as well as being in keeping with the trend that cancer occurs more commonly in older people (Editorial Cancer News, 1986).

DISTRIBUTION OF SEX: Many more female patients (n = 318, 66%) than male patients (n = 164, 34%) were interviewed and this was consistent in all areas (Figure 9). The reasons for this could be that many of the women were housewives who are likely easier to trace at home, or because 37% of patients were over the age of 65 years and women have a greater life expectancy than men (Kaplan & Saddock, 1982).

FIGURE 7: PERCENTAGE BLOCK CHART OF RACE DISTRIBUTION ACROSS RANDOM STRATA

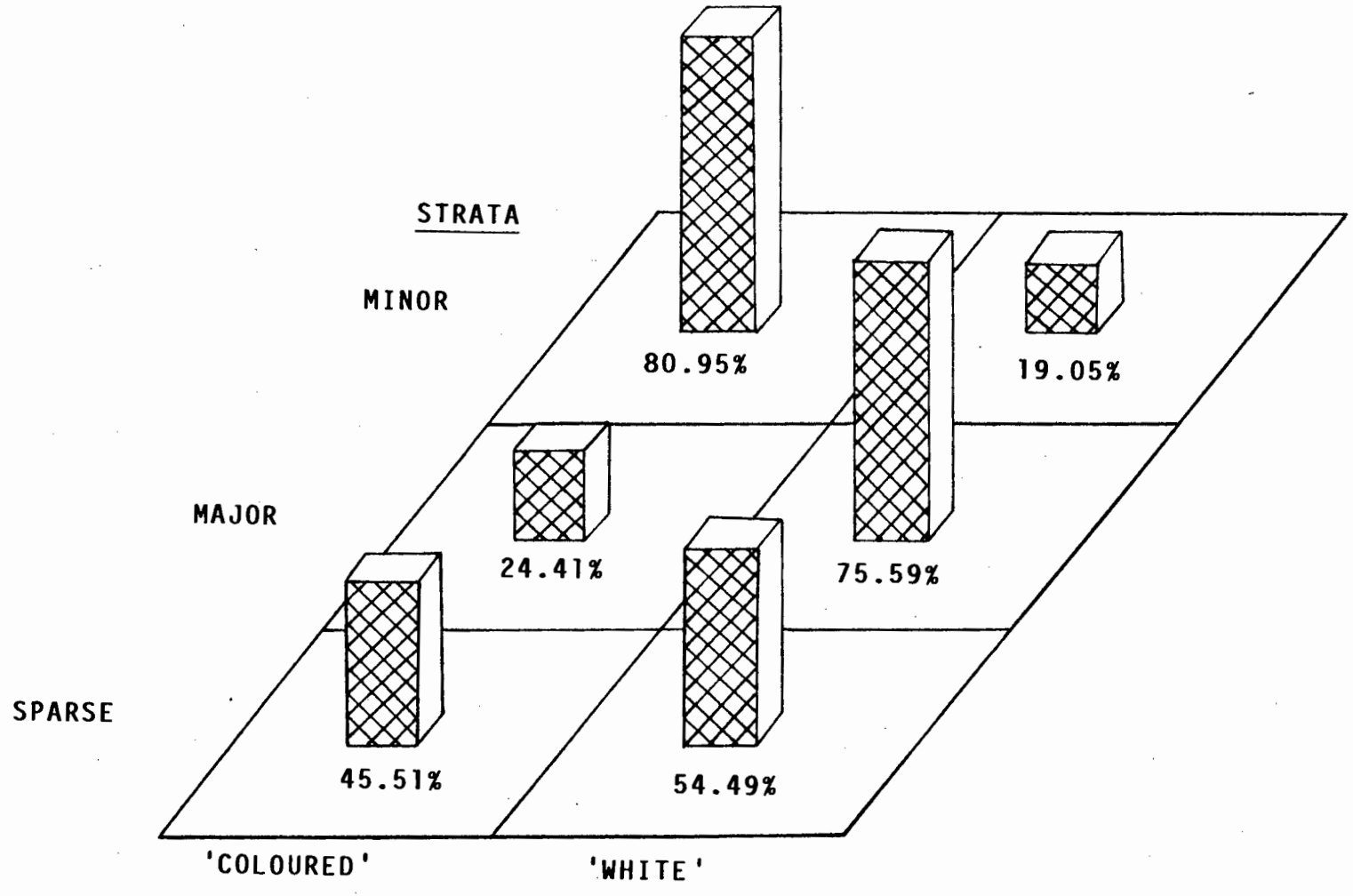


FIGURE 8: PERCENTAGE BLOCK CHART OF AGE DISTRIBUTION ACROSS STRATA

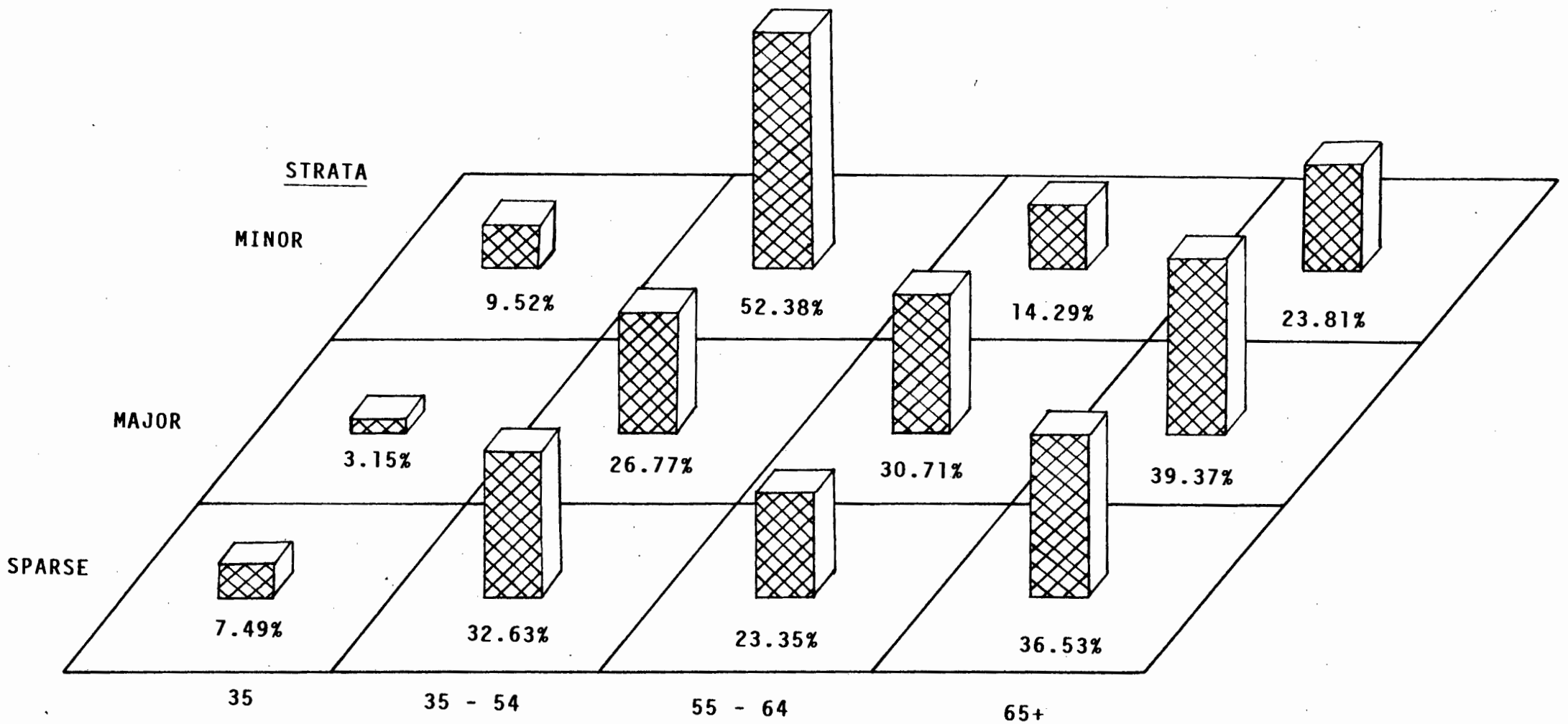
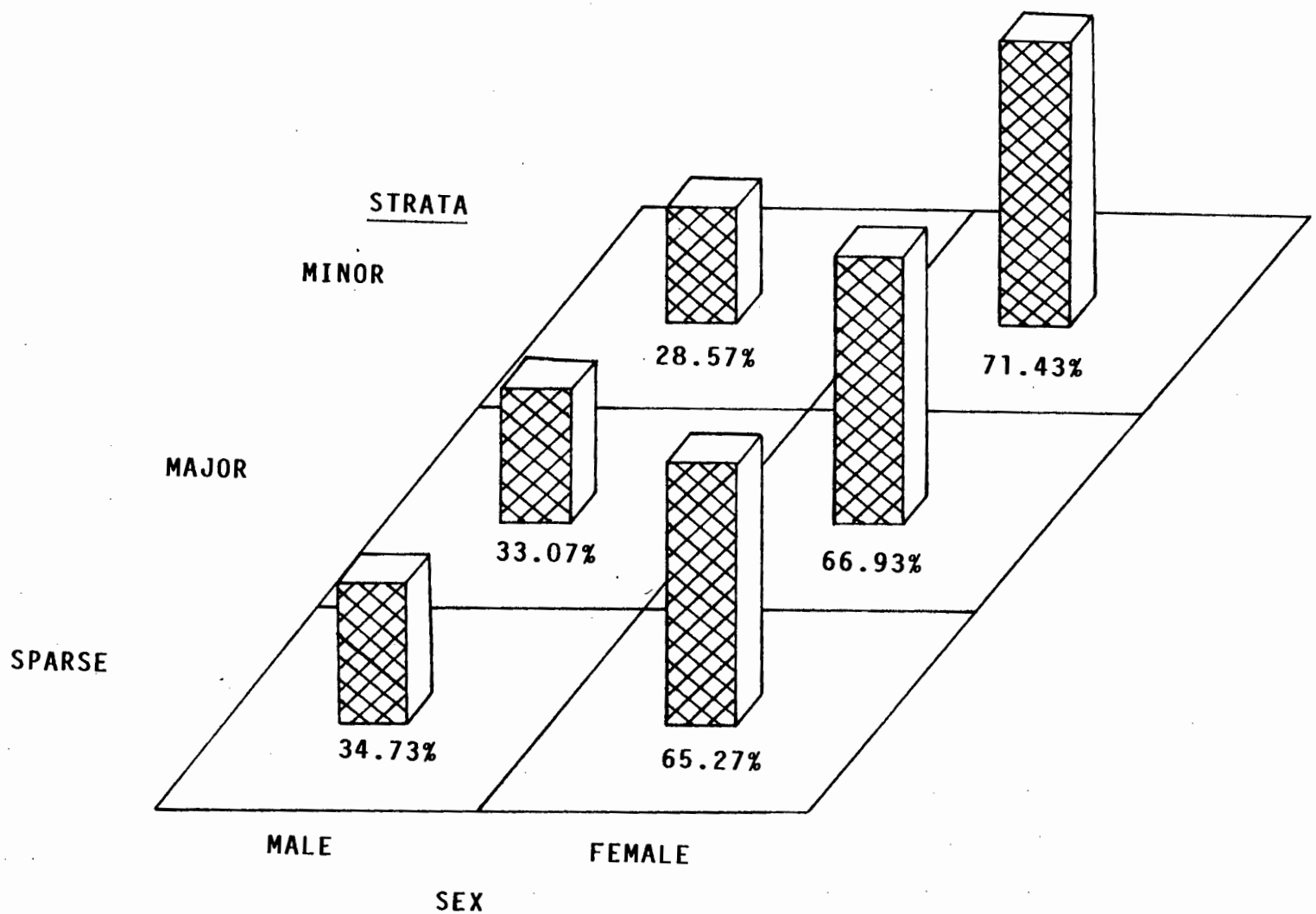


FIGURE 9: PERCENTAGE BLOCK CHART OF SEX DISTRIBUTION ACROSS STRATA



EMPLOYMENT STATUS: Of the patients interviewed, 98 (20%) were employed, 157 (33%) were housewives, 213 (44%) were not employed and 14 (3%) were children or scholars. Patients who were not employed included those who were unemployed, retired or retrenched as a result of being unfit for work (Table 1). Employed patients appeared to constitute the smallest proportion out of the employment status categories and displayed a trend to decrease consistently from the low population density (sparse) areas to the high density areas (major). Conversely unemployment was lower in the low population density than the high population density areas. Housewives appeared to constitute a similar proportion of patients for each stratum i.e. between 33% and 34%. This figure may have been inflated at the expense of the retired category because some females who were clearly of retirement age still regarded themselves as housewives.

5.5.2 Urban Sample (Control Group): 140 Cancer patients who were resident in the Cape Town Metropolitan area were interviewed and comprised the control group. The mean age of the sample was 49 years with 36 patients being employed, 71 not employed,30 housewives and 3 children. 71 of the patients were male, 69 were female and 46 were `coloured', 43 `black' and 51 `white'. The reason that this sample had a lower mean age and a more even sex and racial distrution than the patients in the experimental group was because this group was not randomly sampled but selected to fulfill predetermined criteria of age, sex and race.

## 5.6 ASSESSMENT INSTRUMENTS

5.6.1 Questionnaire for rural cancer patients: A questionnaire was designed to collect information from rural cancer patients on significant practical, medical and emotional problems that they experienced (Appendix A). The questions were based on possible needs and problems of rural cancer patients that had been commented on in the literature (Clement-Jones, 1985; Ganster & Victor, 1988; Goddard, 1986; Kalish, 1981; Lancaster, 1986; Oberst, 1980; Schain, 1981; Silberfarb, 1982; Springer, 1985;

TABLE 1: DISTRIBUTION OF EMPLOYMENT STATUS (RURAL CANCER PATIENTS) N=468.

| Employment status | Number of patients in each stratum | | | |
|---|---|---|---|---|
| | Sparse | Major | Minor | TOTALS |
| *NOT EMPLOYED | | | | |
| Retired | 90 | 46 | 4 | 140 |
| Retrenched | 37 | 16 | 8 | 61 |
| Unemployed | 7 | 4 | 1 | 12 |
| *NOT EMPLOYED | 134(42%) | 66(53%) | 13(62%) | 213 |
| Employed | 81(25%) | 16(13%) | 1 (5%) | 98 |
| Housewives | 107(33%) | 43(34%) | 7(33%) | 157 |
| TOTALS | 322 | 125 | 21 | 468 |

**Please note:** Scholars/student/children (n=14) are excluded from this table.

## 5.7 CHAPTER SUMMARY

A pilot study was done to test research methodology and the design of the assessment instrument. It was not possible to sample rural cancer patients randomly because so little is known about this population so 20 magisterial districts were sampled from 35 districts by stratified random sampling. The sample consisted of 496 rural cancer patients and the urban control group consisted of 140 cancer patients. The number of `black' patients was so small (n=14) that they had to be omitted for analysis of data which was for general interpretation. Demographic factors which must be considered when interpreting the data include the disproportionately high number of `whites' in the major strata. Many patients were of retirement age. A large proportion of the sample were women. Most patients were not employed. Many were housewives and a small proportion were employed. Questionnaires were used to collect information from the patients on practical, medical and emotional needs and problems as well as on perceived stress.

# CHAPTER 6: RESULTS

## 6.1 CHAPTER INTRODUCTION

In this chapter the differences in stress as reported in the different strata, comparative analysis of stress results between rural and urban samples and the relationship between reported stress and needs and problems experienced will be provided.

## 6.2 STRESS BY STRATA (RURAL SAMPLE)

6.2.1 Statistical analysis: The Kruskal-Wallis one-way analysis of variance by ranks (Siegel, 1956) was used for the stastical analysis of this data. The use of a non-parametric test was selected because insufficient information was available on the population being studied. Thus it could not be assumed that the samples were drawn from populations with normal distributions and equal variances (Miller, 1975).

6.2.2 Sparse stratum: 334 Patients from 16 magisterial districts were interviewed while 2 scholars were excluded for the analysis of the employment status categories.

Employed patients reported experiencing more total stress than housewives and not employed patients. Employed patients and housewives experienced statistically significantly more employment stress than patients who were not employed. 'Coloured' patients experienced significantly more total, employment, social and personal stress than 'white' patients. Females experienced significantly more total and employment stress than males and patient in the younger category experienced significantly more total, employment and social stress than the older patients (see Table 2).

6.2.3 Major stratum: 127 Patients from 2 magisterial districts were interviewed while 2 scholars were excluded from the analysis of the employment status categories.

Housewives and employed patients experienced significantly more employment stress than the patients who were not employed. `Coloured' patients experienced significantly more social stress than the `white' patients and females experienced significantly more employment stress than males. In the age category of 50 years or below patients experienced significantly more total, employment, social and personal stress than the older patients (see Table 3).

6.2.4 Minor stratum: 21 Patients were interviewed from 1 magisterial district. While there were many differences in the stress experienced by patients in the various categories, very few of these were significant and this was probably due to the small sample size.

Housewives experienced significantly more stress than the employed and not employed patients and females experienced more personal stress than males (see Table 4).

6.2.5 Summary: The maximum possible total stress score on the SEI was 60 although scores well under 20 appeared to be the most commonly recorded across all strata.

All the variables investigated appeared to have some influence on the amount and type of stress in the cancer patients who were sampled. Employment status had a consistant influence on total stress for the rural sample and for both the urban and the control samples, it had a consistent influence on employment stress (see Table 5). Race and age had a consistent influence on social stress. This was found in the rural and the urban control sample (see Table 6). For both the rural and the urban samples no single variable appeared to have a consistent influence on the personal stress that patients experienced (see Table 6).

## 6.3 COMPARATIVE ANALYSIS OF STRESS

6.3.1 Statistical analysis: The Beslow Day test for the homogeneity of the odds ratio was used for the analysis of this data. This test provided a measure of the degree of

**TABLE 3: TABLE OF EMPLOYMENT, SOCIAL, PERSONAL AND TOTAL STRESS FOR THE MAJOR STRATUM.**

| VARIABLE | N | EMPLOYMENT STRESS | | SOCIAL STRESS | | PERSONAL STRESS | | TOTAL STRESS | |
|---|---|---|---|---|---|---|---|---|---|
| | | Mean | Statistical Significance | Mean | Statistical Significance | Mean | Statistical Significance | Mean | Statistical Significance |
| * Employment Status | | | | | | | | | |
| ** Not Employment | 66 | 1,03 | KW = 12,84 | 2,23 | N.S. | 1,74 | N.S. | 5,00 | N.S. |
| Employed | 16 | 1,94 | DF = 2 | 2,75 | KW = 1,92 | 2,56 | KW = 2,06 | 7,25 | KW = 2,26 |
| Housewives | 43 | 2,28 | P = 0,0016 | 1,63 | DF = 2 | 1,33 | DF = 2 | 5,23 | DF = 2 |
| Race | | | | | | | | | |
| Coloured | 31 | 1,16 | N.S. | 3,26 | KW = 4,12 | 2,19 | N.S. | 6,61 | N.S. |
| | | | KW = 0,96 | | DF = 1 | | KW = 0,61 | | KW = 0,63 |
| White | 96 | 1,74 | DF = 1 | 1,67 | P = 0,0423 | 1,52 | DF = 1 | 4,93 | DF = 1 |
| Sex | | | | | | | | | |
| Male | 42 | 1,29 | KW = 4,02 | 2,14 | N.S. | 1,98 | N.S. | 5,40 | N.S. |
| | | | DF = 1 | | KW = 5,29 | | KW = 0,01 | | KW = 0,00 |
| Female | 85 | 1,75 | P = 0,0451 | 2,01 | DF = 1 | 1,54 | DF = 1 | 5,31 | DF = 1 |
| Age | | | | | | | | | |
| ≤ 50 | 98 | 1,32 | KW = 9,53 | 1,73 | KW = 5,29 | 1,36 | KW = 3,98 | 4,41 | KW = 6,26 |
| | | | DF = 1 | | DF = 1 | | DF = 1 | | DF = 1 |
| > 50 | 29 | 2,55 | P = 0,002 | 3,14 | P = 0,0214 | 2,79 | P = 0,0462 | 8,48 | P = 0,0123 |

* Scholars were excluded for the analysis of employment status.

** "Not Employed" refers to retired, retrenched and unemployed patients.

**Abbreviations** : KW = Calculated Kruskal - Wallis Value.
DF = Degrees of Freedom.
NS = Not significant.
P = At 95% confidence interval.

**TABLE 4: TABLE OF EMPLOYMENT, SOCIAL, PERSONAL AND TOTAL STRESS FOR THE MINOR STRATUM**

| VARIABLE | N | EMPLOYMENT STRESS | | SOCIAL STRESS | | PERSONAL STRESS | | TOTAL STRESS | |
|---|---|---|---|---|---|---|---|---|---|
| | | Mean | Statistical Significance | Mean | Statistical Significance | Mean | Statistical Significance | Mean | Statistical Significance |
| * Employment Status | | | | | | | | | |
| ** Not Employed | 13 | 1,62 | KW = 7,75 | 4,15 | NS | 4,00 | NS | 9,77 | NS |
| Employed | 7 | 3,29 | DF = 2 | 4,57 | KW = 2,54 | 4,43 | KW = 1,77 | 12,29 | KW = 3,02 |
| Housewives | 1 | 16,00 | P = 0,0208 | 11,00 | DF = 2 | 11,00 | DF = 2 | 38,00 | DF = 2 |
| Race | | | | | | | | | |
| Coloured | 17 | 3,29 | NS KW = 0,92 | 5,00 | NS KW = 1,18 | 5,24 | NS KW = 1,32 | 13,53 | NS KW = 2,61 |
| White | 4 | 1,00 | DF = 1 | 3,00 | DF = 1 | 1,25 | DF = 1 | 5,25 | DF = 1 |
| Sex | | | | | | | | | |
| Male | 6 | 0,67 | NS KW = 2,01 | 3,17 | NS KW = 1,39 | 2,00 | KW = 3,98 DF = 1 | 5,83 | NS KW = 3,65 |
| Female | 15 | 3,73 | DF = 1 | 5,20 | DF = 1 | 5,47 | P = 0,0461 | 14,4 | DF = 1 |
| Age | | | | | | | | | |
| ≤ 50 | 9 | 1,11 | NS KW = 1,78 | 3,22 | NS KW = 2,61 | 2,89 | NS KW = 0,76 | 7,22 | NS KW = 2,35 |
| > 50 | 12 | 4,27 | DF = 1 | 5.67 | DF = 1 | 5,67 | DF = 1 | 15,5 | DF = 1 |

* Scholars were excluded for the analysis of employment status.

** "Not Employed" refers to retired, retrenched and unemployed patients.

**Abbreviations** : KW = Calculated Kruskal - Wallis Value.
DF = Degrees of Freedom.
NS = Not significant.
P = At 95% confidence interval.

**TABLE 5: TABLE OF MEAN STRESS BY STRESS CATEGORIES AND EMPLOYMENT STATUS, RACE, SEX AND AGE (URBAN CONTROL SAMPLE)**

| VARIABLE | (N = 140) | Mean Total Stress | Mean Employment Stress | Mean Social Stress | Mean Personal Stress |
|---|---|---|---|---|---|
| * Employment Status | | | | | |
| Employed | 36 | 17,84 | 6,81 | 5,47 | 5,56 |
| ** Not Employed | 71 | 10,78 | 0,55 | 4,59 | 5,64 |
| Housewives | 30 | 10,60 | 2,27 | 4,30 | 4,03 |
| Race | | | | | |
| Coloured | 46 | 12,87 | 2,26 | 5,54 | 5,07 |
| Black | 43 | 14,1 | 2,91 | 6,07 | 5,12 |
| White | 51 | 11,39 | 2,80 | 2,84 | 5,75 |
| Sex | | | | | |
| Male | 71 | 12,99 | 2,68 | 4,55 | 5,76 |
| Female | 69 | 12,42 | 2,64 | 4,90 | 4,88 |
| Age | | | | | |
| ≤ 50 | 67 | 15,3 | 3,75 | 5,82 | 5,73 |
| > 50 | 73 | 10,33 | 1,66 | 3,71 | 4,96 |

* Scholars excluded from this category.

** "Not Employed" refers to retired, retrenched or unemployed patients.

**TABLE 6: TABLE OF EMPLOYMENT, SOCIAL AND PERSONAL STRESS (URBAN CONTROL SAMPLE)**

| VARIABLE | N | EMPLOYMENT STRESS | | SOCIAL STRESS | | PERSONAL STRESS | |
|---|---|---|---|---|---|---|---|
| | | Mean | Statistical Significance | Mean | Statistical Significance | Mean | Statistical Significance |
| * Employment Status | | | | | | | |
| Not Employed | 71 | 0,55 | KW = 78,02 | 4,59 | NS | 5,56 | NS |
| Employed | 36 | 6,81 | DF = 2 | 5,47 | KW = 3,70 | 5,64 | KW = 3,95 |
| Housewives | 30 | 2,27 | P = 0,0001 | 4,30 | DF = 2 | 4,03 | DF = 2 |
| Race | | | | | | | |
| Coloured | 46 | 2,26 | NS | 5,54 | KW = 28,14 | 5,07 | NS |
| Black | 43 | 2,91 | KW = 1,8 | 6,07 | DF = 2 | 5,12 | KW = 1,43 |
| White | 51 | 2,80 | DF = 2 | 2,84 | P = 0,0001 | 5,75 | DF = 2 |
| Sex | | | | | | | |
| Male | 71 | 2,68 | NS | 4,55 | NS | 5,76 | NS |
| | | | KW = 0,08 | | KW = 0,00 | | KW = 1,13 |
| Female | 69 | 2,64 | DF = 1 | 4,90 | DF = 1 | 4,88 | DF = 1 |
| Age | | | | | | | |
| ≤ 50 | 67 | 3,75 | KW = 14,81 | 5,82 | KW = 12,8 | 5,73 | NS |
| | | | DF = 1 | | DF = 1 | | KW = 1,45 |
| > 50 | 73 | 1,66 | P = 0,0001 | 3,71 | P = 0,0003 | 4,96 | DF = 1 |

* Scholars excluded from this analysis of employment status.

**Abbreviations** : KW = Kruskal - Wallis.

DF = Degrees of Freedom.

NS = Not significant.

P = At 95% confidence interval.

**TABLE 7: TABLE OF ODDS RATIOS OF STRESS SCORES: URBAN VERSUS RURAL SAMPLES (95% CONFIDENCE INTERVALS IN BRACKETS)**

| | TOTAL STRESS | EMPLOYMENT STRESS | SOCIAL STRESS | PERSONAL STRESS |
|---|---|---|---|---|
| Crude Odds Ratios | 2,22 (1,41 - 3,49) | 0,85 (0,55 - 1,32) | 2,2 (1,4 - 3,4) | 5,2 (3,3 - 9,3) |
| * Adjusted Odds Ratios | 2,01 (1,25 - 3,23) | 0,83 (0,50 - 1,37) | 2,1 (1,3 - 3,6) | 4,7 (2,9 - 7,8) |

* Ratios Adjusted for Sex, Race and Employment Status.

most commonly experienced problems have been reported on. These were transport difficulties, financial difficulties and the emotional support needs of cancer patients. Even though the rural patient is the focus of attention in this study, information on financial difficulties and emotional support needs was also collected from the urban patients group because these topics were part of the Stress Evaluation Inventory.

6.4.1 Statistical analysis: Frequencies and proportions were calculated to identify the most commonly reported problems. Odds ratios were computed to compare the probability of urban versus rural patients experiencing these problems. Tests for significant differences between means could not be done for this data due to the many interfering and confounding variables. The odds ratios were therefore a useful test to do because they were calculated with statistical adjustments for age, sex, race and employment status.

6.4.2 Transport difficulties: The factors that related to the transport difficulties that rural cancer patients experienced included, time, availability and cost. 91% of patients had to travel some distance for cancer treatment or care. Most patients (77%) spent 4 or more hours per journey to and from the treatment centre that they had to attend and 17% experienced difficulty arranging their transport. Although the cost to the patients varied from nil to hundreds of rands, for some patients, even a small payment represented a severe financial burden.

The mean total stress for patients who experienced transport difficulties was 8,75 (median 7), compared to 5,45 (median 3) for the patients who did not. Odds ratios were calculated and indicated that those patients who had transport problems were 3,2 times more likely to have higher stress than those without these difficulties.

6.4.3 Financial difficulties: 50% of rural and 77% of urban patients reported experiencing financial difficulties

and this problem was the most frequently reported. According to the odds ratios, patients from urban areas were 2,7 times as likely to have financial difficulties. However when unadjusted, the urban areas had only a 1,6 times the odds thereby suggesting that the variables of age sex, race and employment status had a confounding effect. Regarding whether financial difficulties were as a result of the patient developing cancer or not, odds ratios indicated that rural patients were 2,1 times as likely to have financial difficulties due to their illness than urban patients. The highest proportion of rural patients who experienced financial difficulties (71%) was found in the minor stratum where 71% of patients were `coloured', and the lowest proportion (43%) was found in the major stratum where 74% of patients were `white'.

The mean total stress for patients who experienced financial difficulties was 11,09 (median 9), and 5,59 (median 4) for those who did not. Odds ratios revealed that those patients who experienced financial difficulties were 3,3 times more likely to experience higher stress than those who did not.

6.4.4 Emotional support needs: 70% of rural patients reported experiencing a need for emotional support and 91% of these patients reported having this need met. Similar results were obtained in the urban control group where 79% of patients reported needing emotional support and 83% had this need satisfied. However, according to the odds ratios patients in urban areas were 2,5 times as likely to get emotional support than their rural counterparts.

Patients from the rural sample who reported feeling a need for emotional support experienced significantly more mean stress (9,3) than those who did not have this need (5,03). However, 12% of patients reported not receiving the support that they needed and these patients had significantly higher mean stress scores (14,27) than those who received the support that they required (9,33).

6.4.5 Summary: Higher mean stress scores were observed in all instances where patients experienced transport, financial or emotional difficulties. These differences were stastically significant for each variable thereby strongly suggesting that the problems that cancer patients experienced contributed to their already difficult situation.

## 6.5 CHAPTER SUMMARY

The Kruskal-Wallis non-parametric test for significance and the Breslow Day test for the homogeneity of odds ratios were the two statistical procedures that were used. Overall there were some differences in the stress reported in all strata, although this was not significant for the minor stratum. The most commonly reported differences related to employment status, race and sex. The urban patients reported more stress than rural patients and patients who experienced transport, financial and emotional support problems reported more stress than those who did not.

# CHAPTER 7: DISCUSSION

## 7.1 CHAPTER INTRODUCTION

In this chapter a brief summary of the results will be provided. The results will then be interpreted according to the Biomatrix Theory in an attempt to understand the experiences of the rural cancer patient as observed in this study. Emphasis will be placed on identifying the factors which influence the patient's experience and on those parts of the patient which are most affected by these influences. Once these entities have been identified, the Biomatrix Theory will be used to interpret the processes that take place between them.

## 7.2 SUMMARY OF FINDINGS

7.2.1 Geographic and demographic differences in reported stress: The magisterial districts that had a low population density and were situated some distance from cancer treatment centres (sparse stratum), appeared to have many variables which influenced reported stress. Fewer differences in reported stress were found in patients living in areas with higher population densities and closer to treatment centres (major and minor strata). It can therefore be concluded that distance from treatment centres can negatively influence the amount of stress that rural cancer patients report experiencing.

It can also be concluded that variables influencing cancer patients living in urban centres result in these patients reporting even more stress than rural patients. This result seems to be applicable regardless of how far rural patients live from treatment centres.

All of the demographic factors, i.e. employment status, race, sex and age, appeared to influence mean stress to greater and lesser degrees. All employed cancer patients, whether they were housewives or formally employed, reported experiencing high employment stress. Although not found in each of the demographic variable and area combinations,

as a general trend, 'coloured' patients reported more stress than 'whites', women more stress than men and younger patients (50 years or less) more stress than older patients.

7.2.2 The comparison of stress between urban and rural cancer patients: Cancer patients who lived in urban areas reported greater levels of stress than the rural patients. The greatest difference between the two groups was with respect to personal stress. More social stress was also consistently reported in the urban group while the differences in the employment stress was minimal.

7.2.3 The relationship between needs, problems and stress: Factors that were frequently reported by rural cancer patients to be unmet needs or problems were transport, financial difficulties and emotional support. Patients who reported experiencing each of these problems had significantly more reported stress than those who did not.

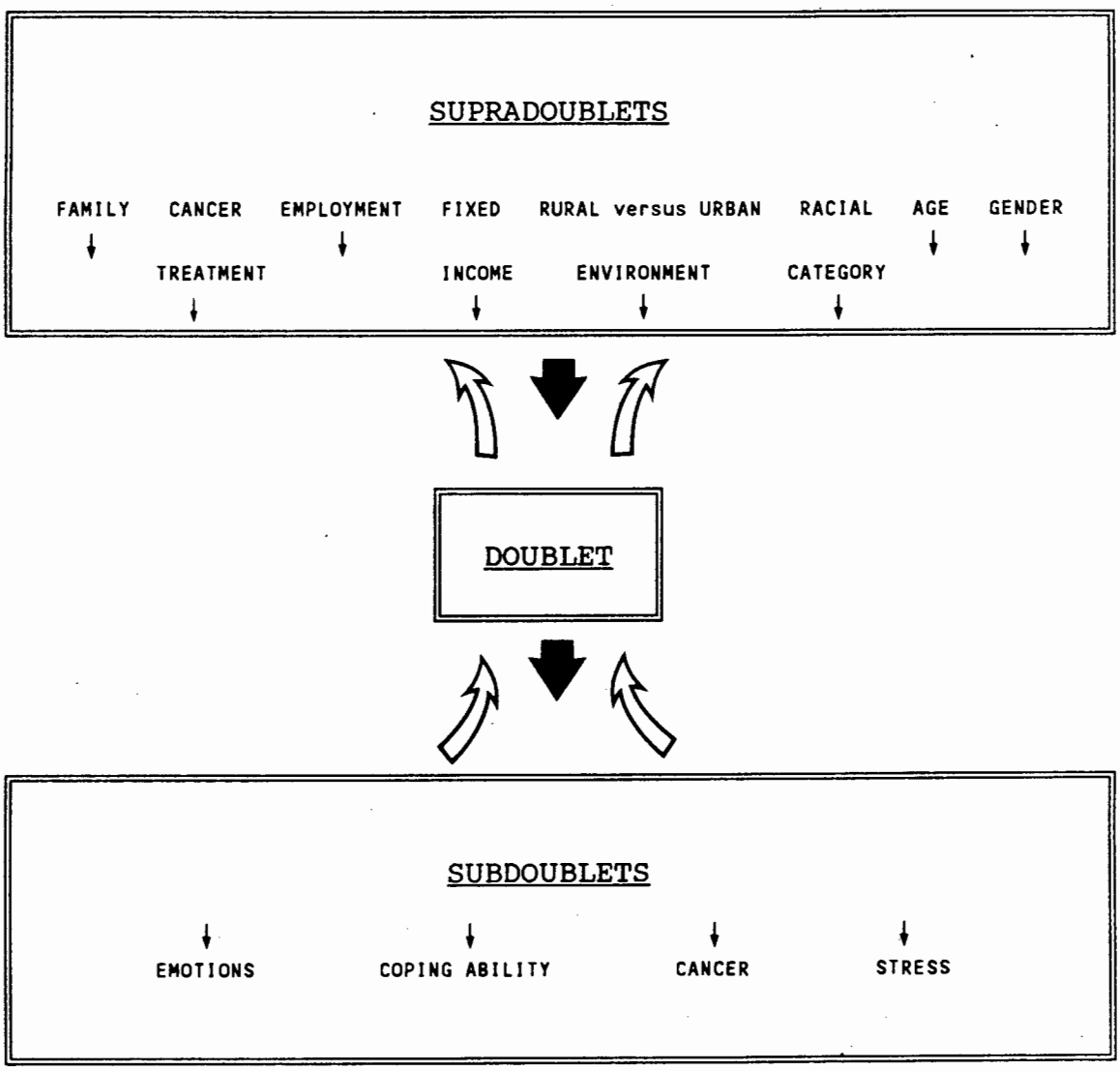
7.3 INTERPRETATION ACCORDING TO THE BIOMATRIX MODEL

7.3.1 STEP 1: The Rural Cancer Patient as the Doublet: The doublet in this study is the rural cancer patient (of the Western Cape). (see Figure 10)

7.3.2 STEP 2: Subdoublets: The most important subdoublets have also been identified from the results of this study as well as from previous research findings. Of the many subdoublets that make up the rural cancer patient doublet, the following have been selected as the most important; emotions, coping ability, cancer and stress. In this study the subdoublet of stress has three subdoublets of its own i.e. employment stress, social stress and personal stress. This means that these three entities are sub-subdoublets in relation to the doublet. (see Figure 10)

7.3.3 STEP 3: Supradoublets: Many supradoublets have some influence on this doublet but based on the review of

Figure 10: The diagramatic representation of the doublet and it's relationship to the supra- and subdoublets. Note that these supradoublets that are illustrated in this diagramme have been selected as being of particular importance to the doublet, but are not the only supradoublets which interact with the doublet. The same applies to the subdoublets which are not the only ones which form part of the doublet.



the literature and the findings of this study, the supradoublets that are included in this interpretation have been selected as the most important. The patient's family, cancer treatment, employment, fixed income, environment, racial category, age and gender have been identified as important supradoublets to the doublet. (see Figure 10)

7.3.4 STEP 4: Needs of the Subdoublets: The subdoublets are the rural cancer patient's emotions, coping abilities and cancer (i.e. disease in the body).

7.3.4.1 EMOTIONS SUBDOUBLET: The needs of this subdoublet include love and support from loved ones, feelings of security in terms of having needs met and of safety by having confidence in the cancer treatment being received (Anastasie, 1979). It is also the need of the emotional subdoublet to have problems solved efficiently so that the doublet is not subjected to excessive frustration which can lead to high levels of emotional distress. It is also important for cancer patients to have somebody with whom they can share their problems so that anxiety can be released and distress can be reduced (Anderson, 1978).

7.3.4.2 COPING ABILITY SUBDOUBLET: This subdoublet needs the doublet to have effective problem solving methods and abilities. This subdoublet also needs personal, social and practical resources to help with the fulfilment of needs and the solving of problems. These resources can be in the form of personal ability, assets such as finances or in the form of family or friends who are willing and able to assist the patient. The primary requirement of this subdoublet is that the doublet respond to the difficult conditions which challenge it by using it's resources to adapt (Blumberg et al., 1981).

7.3.4.3 CANCER SUBDOUBLET: This subdoublet needs a holistic approach to healing with attention given not only to treatment of the cancer cells themselves but also to the total experience of the patient. Health is a complex multidimensional phenomenon involving physical,

psychological and social aspects (Capra, 1987). Physical disease can be balanced by a positive mental attitude combined with social support so that the overall state is one of wellbeing. Capra (1987) suggests that these various dimensions of health will interact and affect one another, and the strongest feeling of being well will be experienced when they are balanced and integrated. Therefore the needs of this subdoublet go far beyond the simple treatment of the cancerous cells. They include the need for social and emotional support, manageable levels of stress, opportunity for emotional and physical relaxation and the development of a positive attitude in the patient. If the whole patient is treated in this way then the body has the optimal circumstances under which it can repair and heal.

7.3.4.4 SUMMARY OF THE SUBDOUBLET'S NEEDS: The needs of the subdoublets were mainly for the doublet to be supported and for the use of a holistic approach to the treatment of cancer. The emotions and coping subdoublets needed the doublet to be emotionally supported, to have effective problem solving strategies and to have practical and emotional resources. The needs of the subdoublets centred around the fact that practical problems can be a source of frustration to the patient but are part of the experience of having cancer in the rural setting. The cancer subdoublet's need for the doublet to have a holistic approach to the treatment of cancer means that it is necessary to regard the practical and emotional care of the rural cancer patient as an essential part of the cancer treatment. It is impossible to say that any one subdoublet is more important than the others as they are parts of the treatment of the whole patient, and are therefore of equal importance.

7.3.5 <u>STEP 5: The needs of the supradoublets:</u> The relative importance of the supradoublets is determined by their needs which have to be met by the doublet. The needs of the supradoublets and the subsequent responses of the doublet result in the processes that take place between

them.

7.3.5.1 EMPLOYMENT SUPRADOUBLET: This supradoublet influences the doublet by providing income in exchange for some work. This work can take many forms and patients who have responsibilities to an employer, (this includes housewives as workers who are employed by the family), are subject to the influences of this supradoublet. The employment supradoublet can make many demands on the doublet in the form of needing attendance at work, productivity, responsibility and accountability. Factors that could influence the rigidity or flexibility of the supradoublet's needs include the position held by the cancer patient as an employee, conditions of service, the financial stability of the employer and the attitude of the employer.

Cancer patients can be discriminated against in the work place in that employers can be reluctant to employ cancer patients because they may need to be absent from work to receive treatment or care. Some patients may have anxieties about remaining employed but in many cases, especially when patients are feeling unwell, work can be a source of chronic stress to cancer patients (Cooper & Baglioni, 1988; Ganster & Victor, 1988). This stress can be caused by worries about performance, from the effort of keeping up with the demands of the job, or simply from the usual tensions that are generated in the workplace (Musci, 1985). The stress related to working (or job stress) was demonstrated in this study by housewives and employed patients reporting significantly more total and employment stress than the patients who were retired or unemployed.

The employment supradoublet does not only pose problems and challenges but can also provide great rewards for the doublet. Being able to work is important to many patients because it provides valuable income and can be a major means of personal identity and self realization. Western society places a high premium on both financial and psychological independence, generally blurring the two

(Fobair & Cordoba, 1982). The fact that the roles associated with work may be very important indicates that should patients be unable to work this can be a major loss for them (Cooper & Baglioni, 1988).

7.3.5.2 FIXED INCOME SUPRADOUBLET: This supradoublet includes patients who receive their income from a pension, insurance or disability grant. This kind of income is usually fixed. The only demand that it makes on the doublet is that patients must qualify in terms of the associated regulations to receive the income.

7.3.5.3 FAMILY SUPRADOUBLET: The need of the family as a supradoublet is to have access to the patient and to receive some response from the patient. The family also need information about the patient's problems and condition (Van Den Born, Pruyn & Meijk, 1986) so that they can be involved as a resource and also play a supportive role.

7.3.5.4 CANCER TREATMENT SUPRADOUBLET: The primary need of this supradoublet is to have the patient's consent, co-operation and attendance for treatment. This supradoublet also needs payment from the patient although this is a flexible need depending on the patients financial circumstances. Most conventional cancer treatments are provided by large treatment hospitals and are heavily subsidised by the state. If patients have strained financial circumstances then application may be made to have the fees reduced or even waived.

7.3.5.5 RACE SUPRADOUBLET: This supradoublet can affect the doublet by influencing the practical, social and emotional experience of having cancer. In the South African context laws, social pressure and historical development of discrimination has a profound effect on the lives of all people. Due to legislative and administrative policy, some medical services are racially segregated eg. local rural clinic and hospital facilities.

While many services are not legally segregated, social

circumstances can result in segregated use, eg. ambulance and kombi transport services tend to be used primarily by patients from the `coloured' population group because this group is generally poorer than `white' patients who use motor cars or trains as preferred modes of transport (Edwards, 1987). Because of the political and economic development in rural areas of the Western Cape the `coloured' community constitutes the bulk of the farm labourers or unskilled labour for small town business or industry (Edwards, 1987). This could explain the reason why in the areas of this study where most of the cancer patients were `coloured', a significantly higher frequency of financial difficulties was reported. This group is frequently without financial resources and is usually dependent on sources outside of the family for assistance with transport, finance and other practical needs (Edwards, 1987). In this study the `coloured' patients who lived in distant and isolated regions reported experiencing significantly more stress than the `whites' from the same areas. This stress included employment, personal and socially related stress. In the more urbanised rural areas, `white' patients reported fewer practical and financial problems than `coloured' patients who reported experiencing significantly more social stress than the `white' patients. Generally, in the samples of mostly `white' patients fewer practical and financial problems were reported whereas, where most of the patients were `coloured', <u>many</u> more practical and financial problems were reported.

These results seem to support the idea that race and socio-economic status may be closely connected in some of the rural areas that were studied. Therefore the rural cancer patient's experiences may be negatively affected by the race supradoublet in the form of the social, situational or historical influences of racial discrimination.

7.3.5.6 AGE SUPRADOUBLET: The influence of the age supradoublet is profound because, not only is cancer more

common in older people, but when older people get cancer, symptoms of ageing such as weakness, fatigue and dependency on others, can be aggravated or even brought on prematurely (Edwards, 1987). The effort of travelling, perhaps under uncomfortable circumstances, and being away from home for extended periods can be difficult or even overwhelming for older people. Older patients do not always have sound support systems, as spouses may have died and children may have moved away, leaving the ageing patient isolated and without resources. In contrast to older patients, younger patients may have other difficulties to cope with such as young children to care for, jobs to maintain or studies to complete. In this study younger patients who lived in distant and isolated areas reported higher total, employment and social stress. Older patients who lived in the more urbanised and densely populated areas reported more stress than the younger patients. The doublet is therefore influenced in a variety of ways by the age supradoublet although these influences are probably because more younger patients are employed than the older patients, many of whom were retired.

7.3.5.7 GENDER SUPRADOUBLET: The gender of rural cancer patients present certain influences for the patient to respond to. Traditional sex roles have generally been dictated by economics and have resulted in most men being the family's main source of income and security. Women have traditionally cared for the welfare of the husband and children at home. This dupradoublet therefore demands that the doublet fill the appropriate sex role. Being a cancer patient can place strain on the traditional family sex roles and from the results of this study it appears that the women do not adapt as well as men. In the more distant and isolated areas, women reported higher total and employment stress than men. In the densely populated areas, both with and without treatment centres, women reported experiencing more total stress.

7.3.5.8 RURAL VERSUS URBAN SUPRADOUBLET: The urban patients had a higher chance of experiencing stress than

7.3.6 STEP 6: FULFILLMENT OF THE NEEDS OF THE DOUBLET

One of the goals that most cancer patients have is for a good quality of life (Brewin, 1986). Quality of life depends very much on how the patient feels, how content they are and how much they can do. While the doublet has many needs the most pressing ones relate to receiving treatment, coping practically and emotionally so that good quality of life can be experienced.

Financial difficulties were the most commonly reported problem in this study. This suggests that the process of obtaining income is very important for rural cancer patients. Finances also appeared to be important in the influence of the race and gender supradoublets in placing strain on the doublet with respect to practical and financial difficulties. The employment supradoublet or the fixed income supradoublet provides for the doublet's income, and therefore for the financing of the doublet's living, medical and other expenses. The cancer treatment supradoublet provides for the doublet's need for cancer treatment but for this to occur it is very important that patients are able to travel to the treatment centres. The fact that patients have to travel away from their homes to receive treatment, has major implications for their emotional support needs. Usually the family provides for the emotional needs of the doublet as well as providing valuable resources for seeking solutions to problems and for meeting many of the patient's needs. When the family is not available the patient can be completely isolated from support and may look to the treatment care team to provide the needed support (Woody & Springer, 1985).

Therefore the important processes in the satisfying of the needs of the doublet by the supradoublets are the transport to treatment teleon, the emotional support teleon and the income teleon.

7.3.7 Teleons within the doublet: While exoteleons and endoteleons exist within the doublet, the teleons which have been identified as important are all endoteleons.

They are endoteleons because the satisfaction of their purpose is directed towards the doublet i.e. towards the purposes of the rural cancer patient.

7.3.7.1 TRANSPORT TELEON: The ultimate goal of the transport teleon is to get the patient to the treatment centre so that treatment for the cancer can be provided. The problems that could occur to minimise the chances of the teleon reaching it's goal include the patient having insufficient finances for transport (interference with matter), lack of information about transport services (interference with information), unavailability of transport services in outlying areas (interference with matter) or patients not feeling well enough to make the long journey (interference with energy).

7.3.7.2 FINANCES TELEON: The process of obtaining money to pay for living, medical or other expenses constitute the finances teleon. Various patients obtain income from a variety of sources such as being employed, pension schemes, state grants or private investment income. The expenses relating to having cancer can be direct expenses related to the disease such as medicines or indirect expenses such as transport costs, loss of income or special equipment. The problem in this teleon arises when income is not sufficient to meet expenses and as a result, high levels of stress are experienced in the teleon.

The main difficulties that can arise to prevent the finances teleon from reaching it's goal can be the reduction in the patient's income due to eg. loss of a job (interference with structure), or to the increase in expenses in excess of the patients income and financial resources (interference with matter).

7.3.7.3 EMOTIONAL SUPPORT TELEON: This teleon represents the processes that occur when rural cancer patients receive emotional support. The goal of this teleon is to provide whatever emotional support the patient might need on an ongoing basis, or in crisis situations.

The main area where the emotional support teleon can break down in the doublet is when patients have to spend extended periods away from home when they are having diagnostic tests, receiving treatment or need to consult a cancer specialist (interference with information and energy). In these circumstances the family unit is divided with the patient isolated from the most valuable source of emotional support (Woody & Springer, 1985). Even when a family member accompanies the patient, this results in the division of the family and loss of security that a supportive family can provide.

7.3.8 Transfer of telentropy between teleons: Teleons can be associated with one another if the transfer of telentropy takes place between them.

7.3.8.1 TRANSPORT TELEON: This teleon is very important in the context of this study as 91% of the patients interviewed had to travel to treatment centres for care. Transport problems were a major source of stress for patients. Rural patients were especially at risk for difficulties in this area because of the distances that they had to travel. Those patients who had difficulties regarding transport had significantly more reported stress than those who did not. In this way telentropy was transfered from the transport teleon to the emotional state teleon of the patient as a result of the difficulties that were experienced (see Figure 11). Telentropy can be transferred from the transport teleon to a variety of teleons depending on the problem that is experienced. An example of this is the important area of the financing of transport. Transport to treatment centres is essential for many patients. Because of the costs involved many patients have to regard the financing of transport as a priority in terms of allocating income (see Figure 12). If the financial income of patients is not sufficient to meet the expenses, it can result in telentropy being transferred to other teleons (see Figure 13). Telentropy can also be transferred to more than one teleon if these teleons are involved in the problems of the transport

Figure 11: This figure illustrates how telentropy in the transport teleon can increase telentropy in another teleon. (1) The patient has no transport and finds this problem difficult to solve. As a result telentropy is increased in the teleon reducing it's chances of reaching it's goal. (2) Telentropy can then be transferred to the emotional state teleon causing the patient to worry about the problem, (3) thereby raising telentropy in the emotional state teleon and reducing it's chances of reaching the goal of emotional stability.

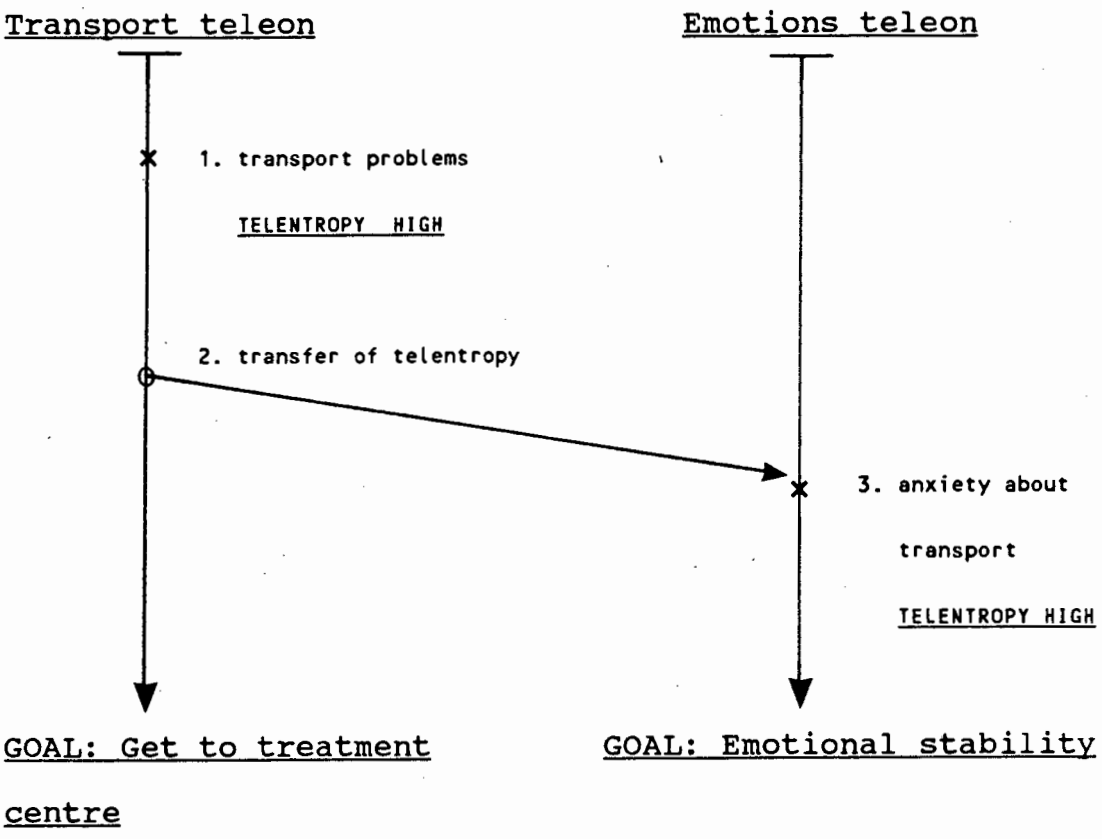


Figure 12: This figure illustrates the transfer of telentropy from the transport teleon to the finances teleon. (1) The patient needs a ticket for the train to travel from a rural area such as Kenhardt to a large treatment centre such as Cape Town. Telentropy is high in the transport because the goal of the teleon cannot be reached without the ticket. (3) Telentropy is then transferred to the finances teleon and income is used to buy the ticket. This places a strain on the finances teleon because income may be limitted and telentropy becomes high in the finances teleon. (4)Because the ticket has been bought the the telentropy in the transport teleon is reduced because the teleon has a good chance of reaching it's goal. Therefore telentropy in the transport teleon has been reduced at the expense of the finances teleon.

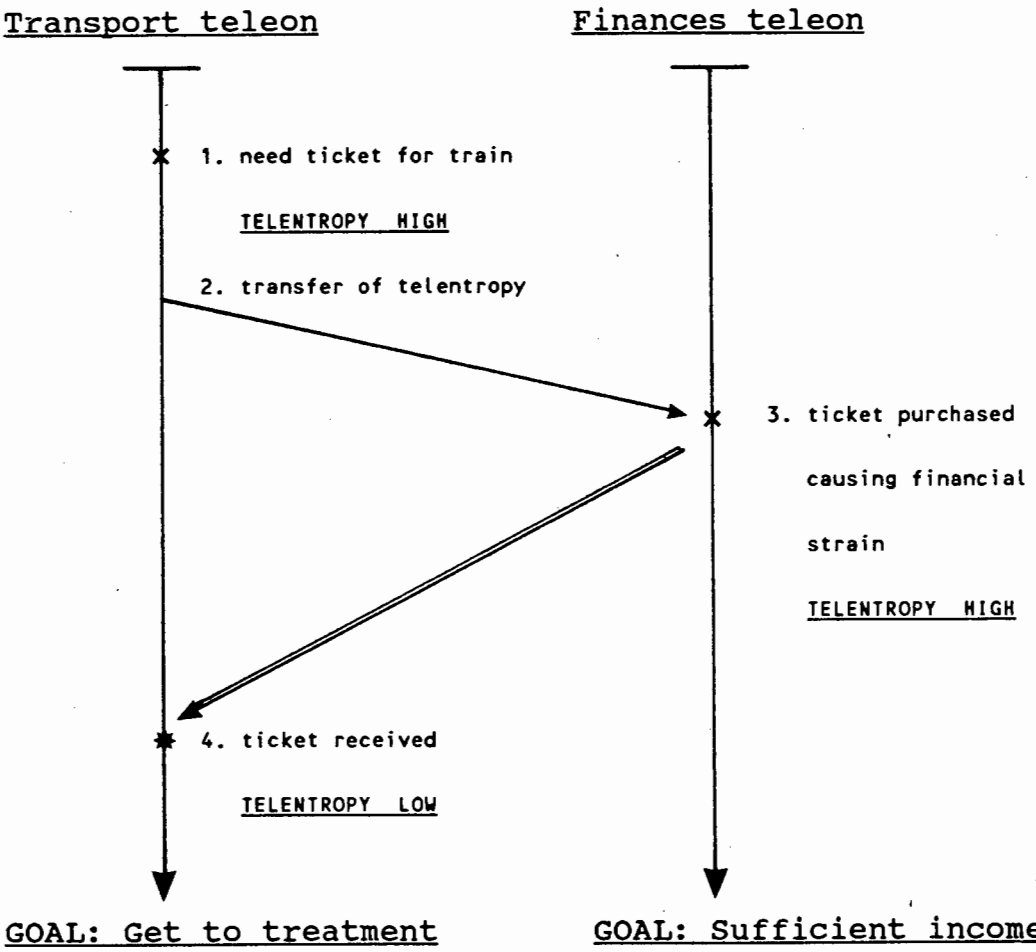
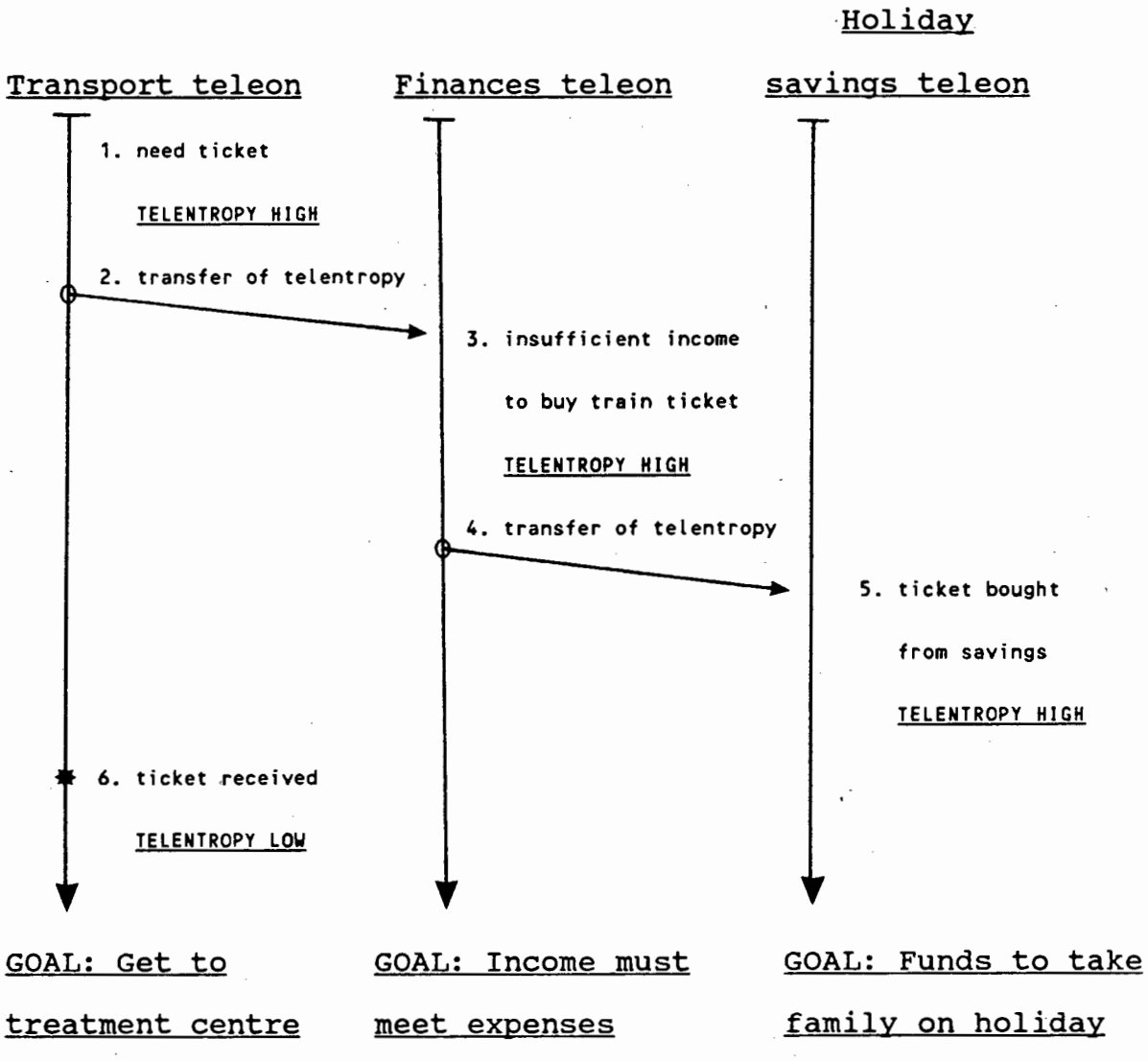


Figure 13: This figure illustrates how telentropy can be transferred via teleons. In this example the patient (1) needs a ticket for the train to travel to the treatment centre. (2) Telentropy is then transferred to the finances teleon and it is discovered that there is (3) insufficient income to meet this expense thereby raising telentropy in this teleon. (4) Telentropy is then transferred to the holiday savings teleon and money is then taken from this resource to pay for the ticket. (5) Telentropy therefore is increased in the holiday savings teleon because funds have been diminished reducing the chance of the teleon reaching it's goal. (6) The train ticket is received resulting in a reduction in the telentropy in the transport teleon as this teleon now has a high chance of reaching its goal.



teleon (see Figure 14 & 15). The process of transport to the cancer treatment centre is therefore closely connected to and influenced by, many teleons. The most important are the finances teleon and the emotions teleon (see Figure 16). The transport teleon is also closely related to the emotional support teleon but this will be discussed in more detail later in this chapter.

7.3.8.2 FINANCES TELEON: The cost of medical and other expenses can be a severe financial burden for the patient and the family (Fobaire & Cordobac, 1982). Rural patients were found to be more likely to have financial difficulties because of their illness. This is possibly due to the additional non medical expenses. Most cancer patients have some medical expenses although costs can vary greatly between patients. These variations can depend on the care that they need or the tariff that is applied to their income group if they receive treatment from a Provincial hospital. It is probable then, that the non medical expenses incurred by rural cancer patients, is more likely to explain why they experience more financial difficulties than urban patients. Non medical expenses can be a heavy and unexpected burden to rural cancer patients because of their many practical needs such as transport and needs associated with being away from home for extended periods for treatment or care. Previous studies (Fobaire & Cordobac, 1982) revealed that 50% of patients spent 25% of their annual income on indirect costs such as transport, special equipment, loss of income and other non medical expenses (see Figure 17). This can severely aggravate the financial burden caused by medical expenses. This, as was found in this and previous studies, can result in high levels of stress in the patient (Elovanio, Hosti, Taskinen & Vontilainen, 1977) (see Figure 18).

Besides the monetary aspects of finances, the process of being employed to earn money can also be an important source of telentropy for the finances teleon. Stress is not to be found in the situation or in the person but rather in the interaction between the two (Vachon, 1987).

Figure 14: This figure demonstrates the transfer of telentropy from one teleon to two other teleons. (1) A patient may feel uncomfortably hot in the transport bus raising telentropy in the transport teleon. (2) Telentropy is then transport to a practical needs teleon because the patient needs a cool drink. (3) The bus does not stop and therefore the patient cannot have the discomfort relieved and thereby (4) transferring telentropy to the emotional state teleon becomes of (5) the feelings of anxiety that the situation generates. (6) Eventually the bus is very close to it's destination lowering telentropy in the transport teleon but the goals of the other two teleons have been frustrated resulting in high telentropy.

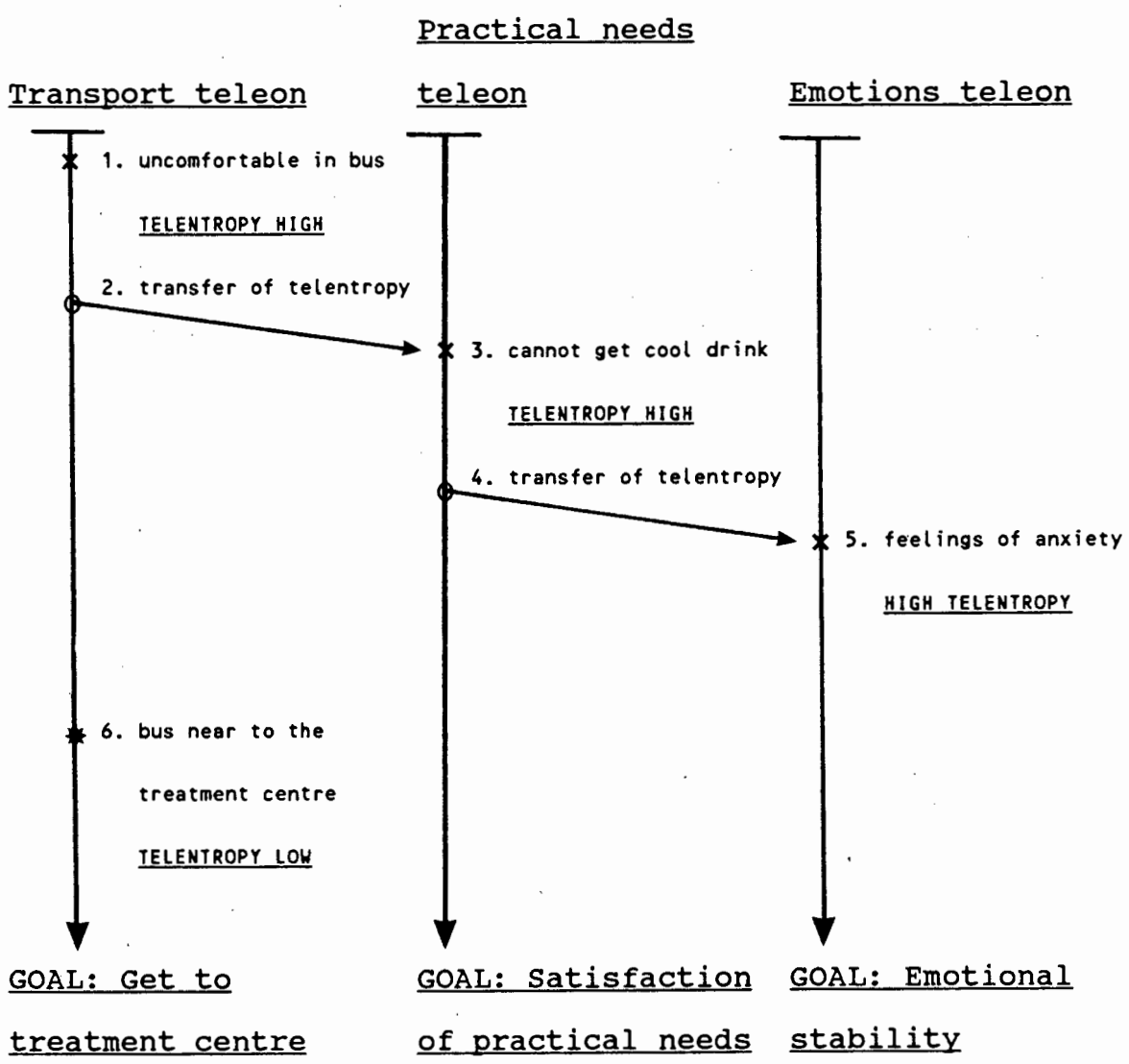


Figure 15: This figure illustrates how the resource teleon absorbs much of the practical and emotional telentropy thereby enhancing their chances of reaching their respective goals. (1) If a patient has no information regarding the availability of transport to hospital, telentropy will be high in the transport teleon. (2) Telentropy is transferred to the resources teleon when the patient appeals to a friend to help. (3) The friend explores the problem and telentropy increases in the resources teleon. (4) The friend then arranges a lift for the patient to the treatment centre but (5) en route the car breaks down raising telentropy in the transport teleon (6) and transferring telentropy to the resources teleon. (7) The patient becomes worried about being late for the treatment appointment and telentropy increases in the emotions teleon. (8) However the car is repaired without much delay, (9) the patient feels less anxious and telentropy becomes lower in both the transport and the emotions teleons.

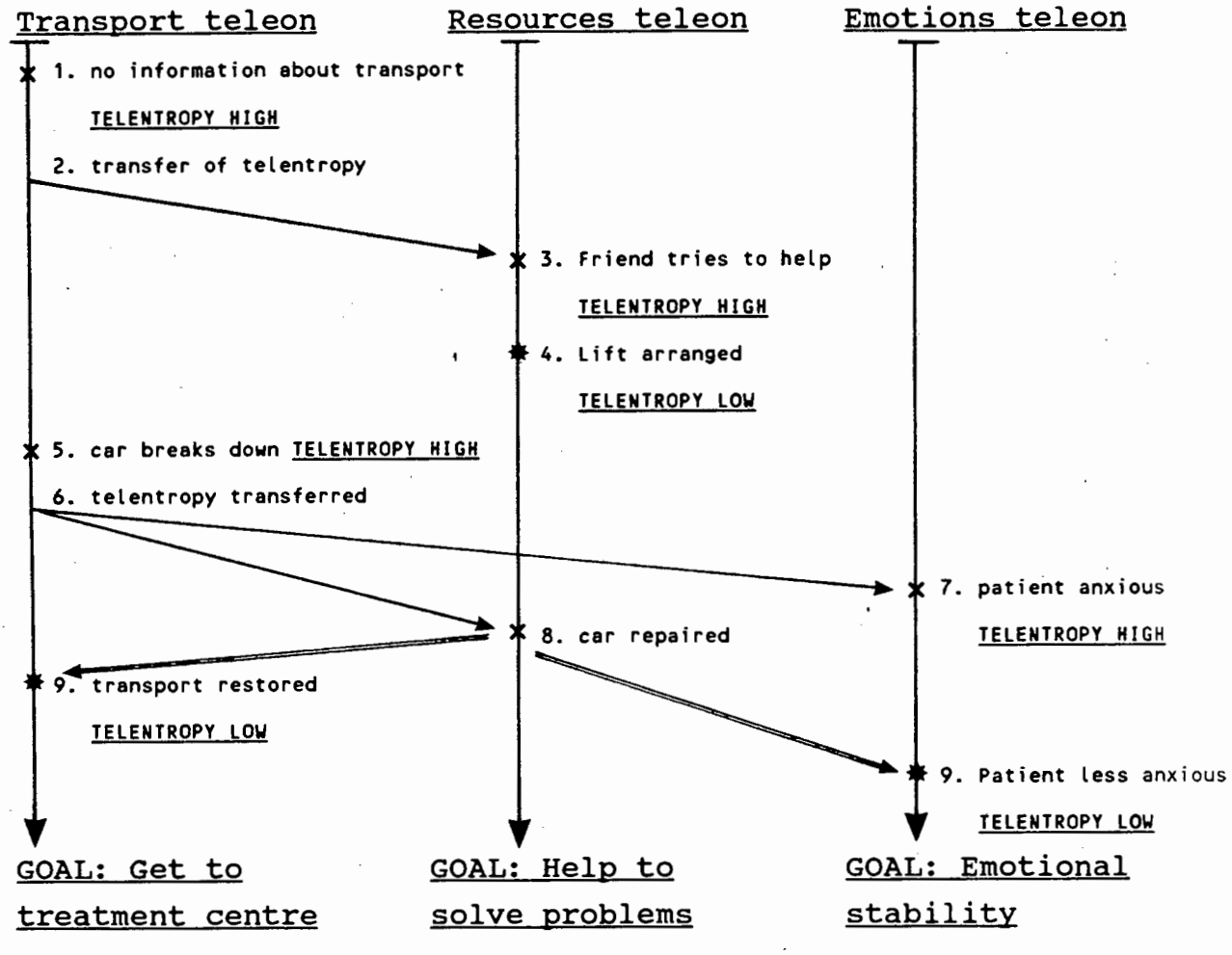


Figure 16: This figure demontrates the close association between the the transport, finances and the emotional support teleons. (1) If a patient needs to purchase fare for transport to hospital then telentropy becomes high in the transport teleon and (2) is transferred to the finances teleon. (3) If this expense is a strain then telentropy willbe high. (4) Telentropy is then transferred to the emotions teleon due to (5) the patient"s anxiety about finances resulting in high telentropy in the emotions teleon. (6) If the patient leaves the family (7) a transfer of telentropy can occur because of the emotional (8) upset and the resultant high telentropy in the emotions teleon. (9) If the patient has to miss work and lose income this can cause (10) a transfer of telentropy to the finances teleon (11) due to financial strain, (12) which can in turn cause a transfer of telentropy to the emotions teleon (13). Therefore the transport teleon has low telentropy because of it's high chance of reaching it's goal, while the emotions and finances teleons have high telentropy with poor chances of reaching their goals.

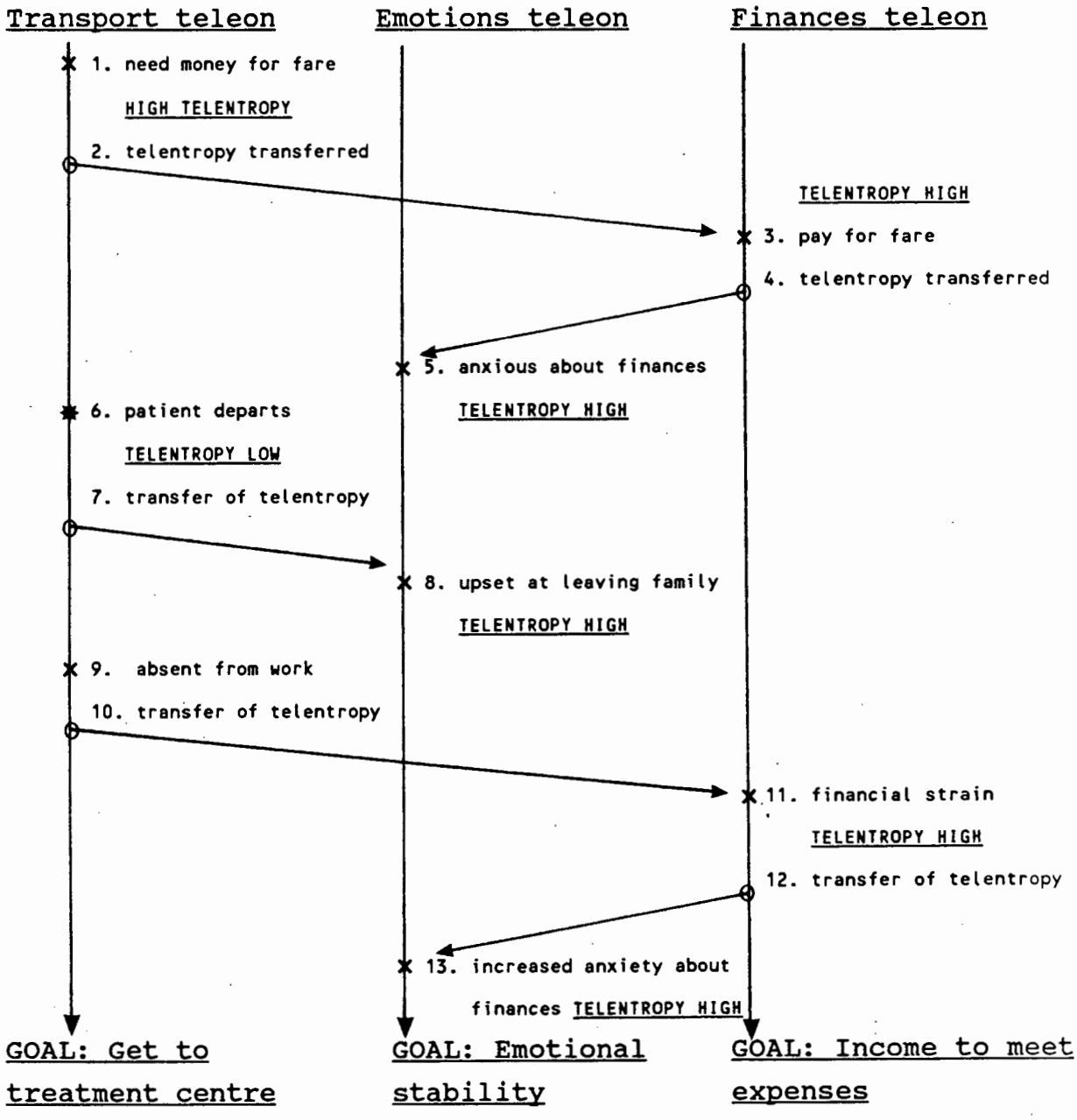


Figure 17: This figure illustrates how the non medical requirements of rural cancer patients can cause telentropy in other teleons. When a patient needs items such as (1) a wig because of hair loss and new pajamas for hospital or (2) telephone calls to home, this results in telentrop being transferred to the (3) finances teleon and (4) ultimately to the emotions teleon. When large amounts of telentropy have been transferred into a teleon, the chances of that teleon reaching it's goal is very small.

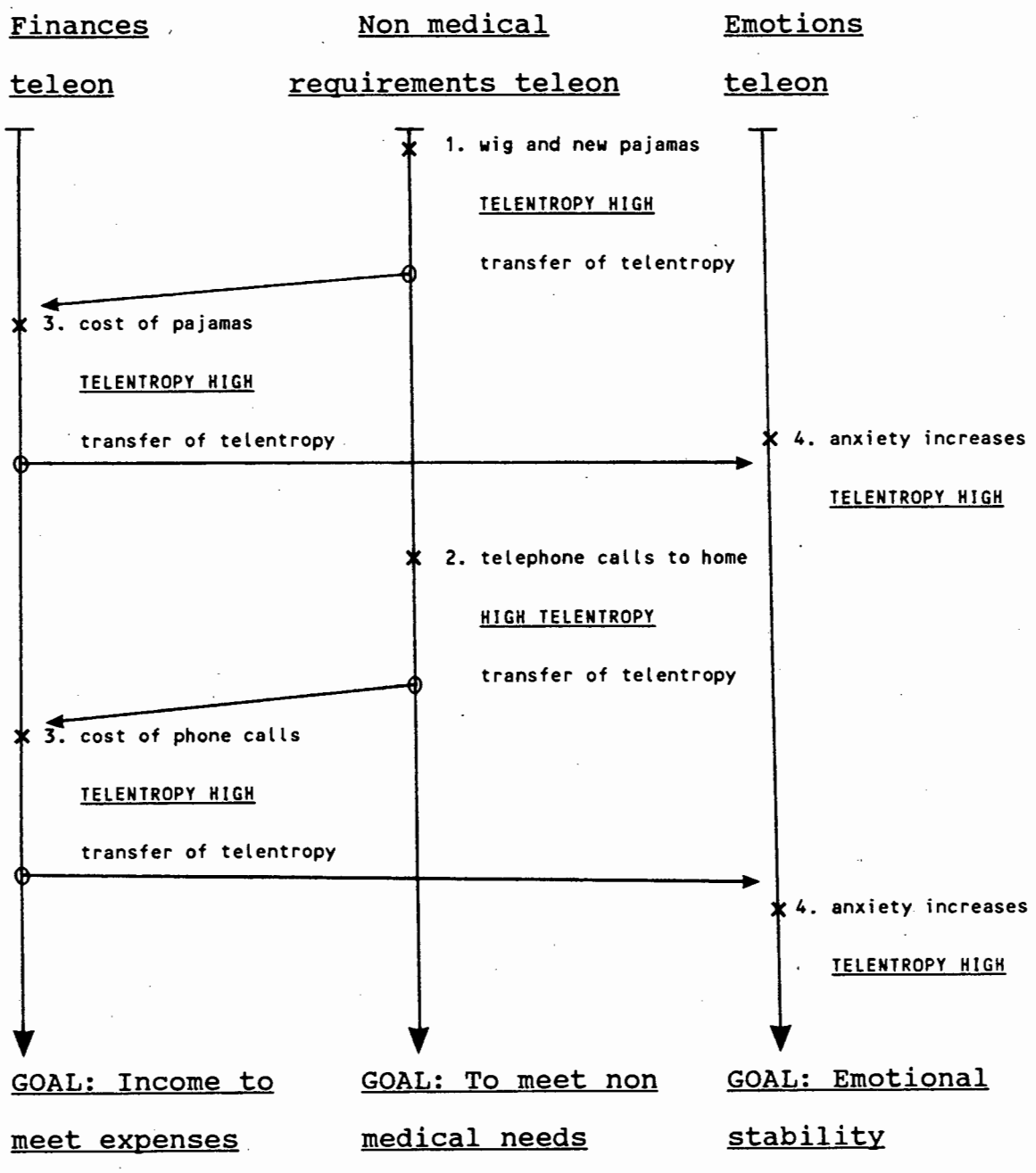
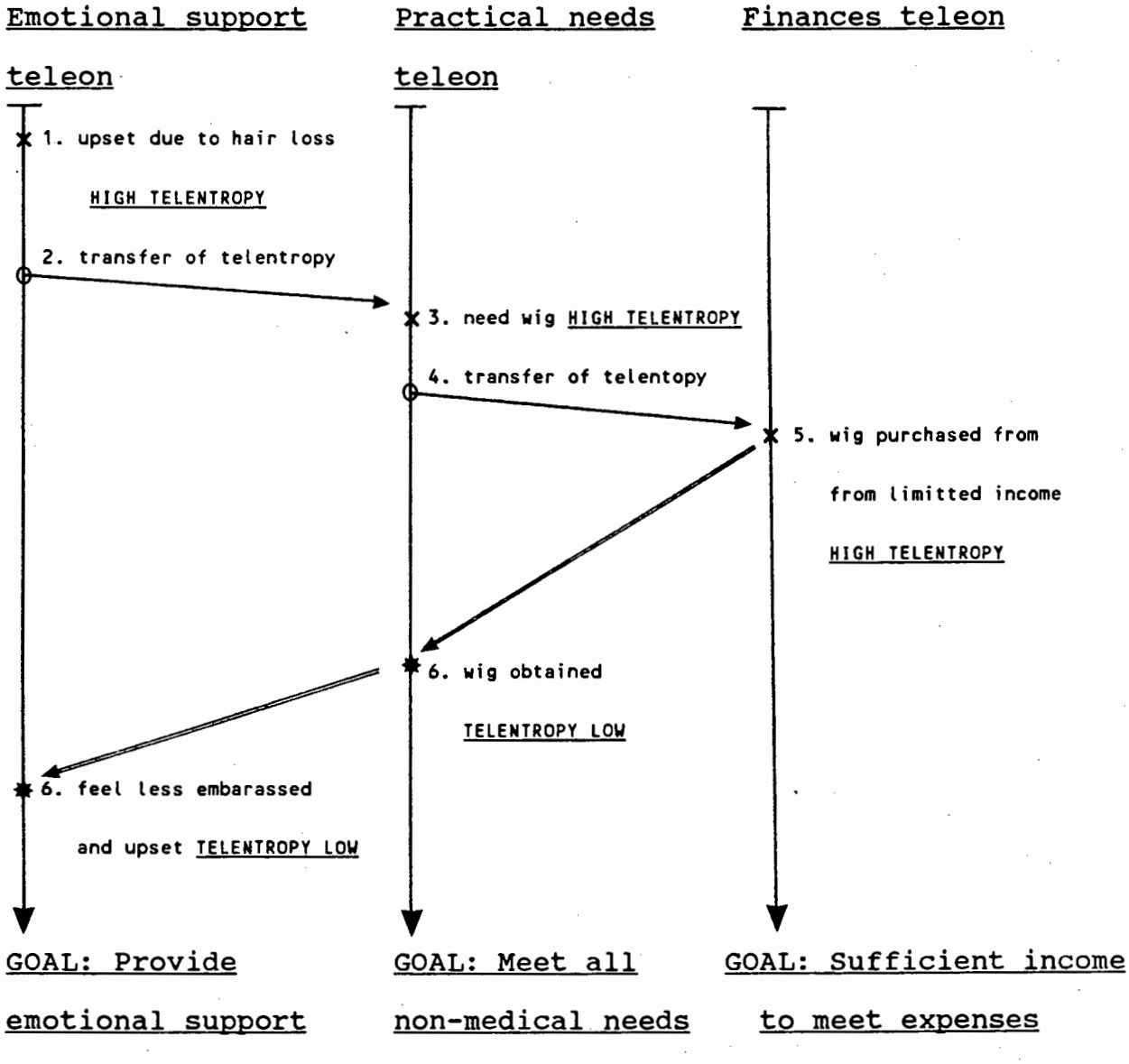


Figure 18: This figure illustrates how the financial burden of non-medical expenses can result in high emotional stress. (1) Should a patient be ambarrassed and shy about loss of hair due to the chemotherapy treatment, then telentropy will be high in the emotions teleon. (2) Telentropy is then transferred to the medical needs teleon because (3) the patient needs to obtain a wig. (4) Telentropy is then transferred to the finances teleon and (5) the wig is purchases placing a financial burden on the finances of the family and causing high telentropy in the finances teleon. (6) However as the wig has been obtained the patient's embarrasment is relieved and telentropy becomes low in the non-medical needs and the emotions teleons.



The employment situations that patients may be in and how they respond to the demands that are made on them in the work place can determine the telentropy that will be generated into the finances teleon by the employment teleon (see Figure 19).

The influence of the finances teleon on the quality of life of cancer patients can be seen by the many ways that telentropy can be received into the financial teleon and generated out of it to other teleons. This demonstrates the importance of finances in providing patients with needs which can be for something frivolous, such as pretty pajamas for hospital, to some very basic needs such as transport to receive what could be life saving treatment.

7.3.8.3 EMOTIONAL SUPPORT TELEON: All patients benefit from interest and empathy (Brewin, 1986). Patients who believe that they are loved and esteemed members of a caring group can be defined as being emotionally supported by that group (Vachon, 1984). Support has been seen to help with concrete tasks as well as emotional needs. If positive, constructive and affirming support is provided then this can help patients to cope with the life events that face them (Bluglass, 1986).

The findings in this study revealed that the cancer patients who needed emotional support reported being more stressed than those who did not. Furthermore, patients who reported that they did not receive emotional support reported having significantly more stress than those who received support (see Figure 20). These findings are supported by a variety of research where lack of support has been found to cause emotional distress and the provision of support has seen to be a buffer against illness (Milne et al., 1986; Pilisuk & Parks, 1983; Woody & Springer, 1985).

As almost all rural cancer patients have to travel away from home for certain periods they have a high risk of losing direct access to their families. The family is

Figure 19: This figure illustrates the process when patient's physical conditions affect their productivity, emotional state and ultimately their income. (1) When patients do not feel well and are not able to work effectively high telentropy occurs in the employment teleon. (2) Telentropy is the transferred to the emotions teleon because of the (3) anxiety that is felt and therefore telentropy becomes high in the emotions teleon. (4) Should the fact that the patient is anxious further upset the ability to work effectively, (5) then more telentropy is transferred into the employment teleon as (6) productivity drops further. Should the patient be unable to cope with work at all then (7) telentropy will be transferred to the finances teleon (8) as the patient's income ceases resulting in high telentropy in this teleon.

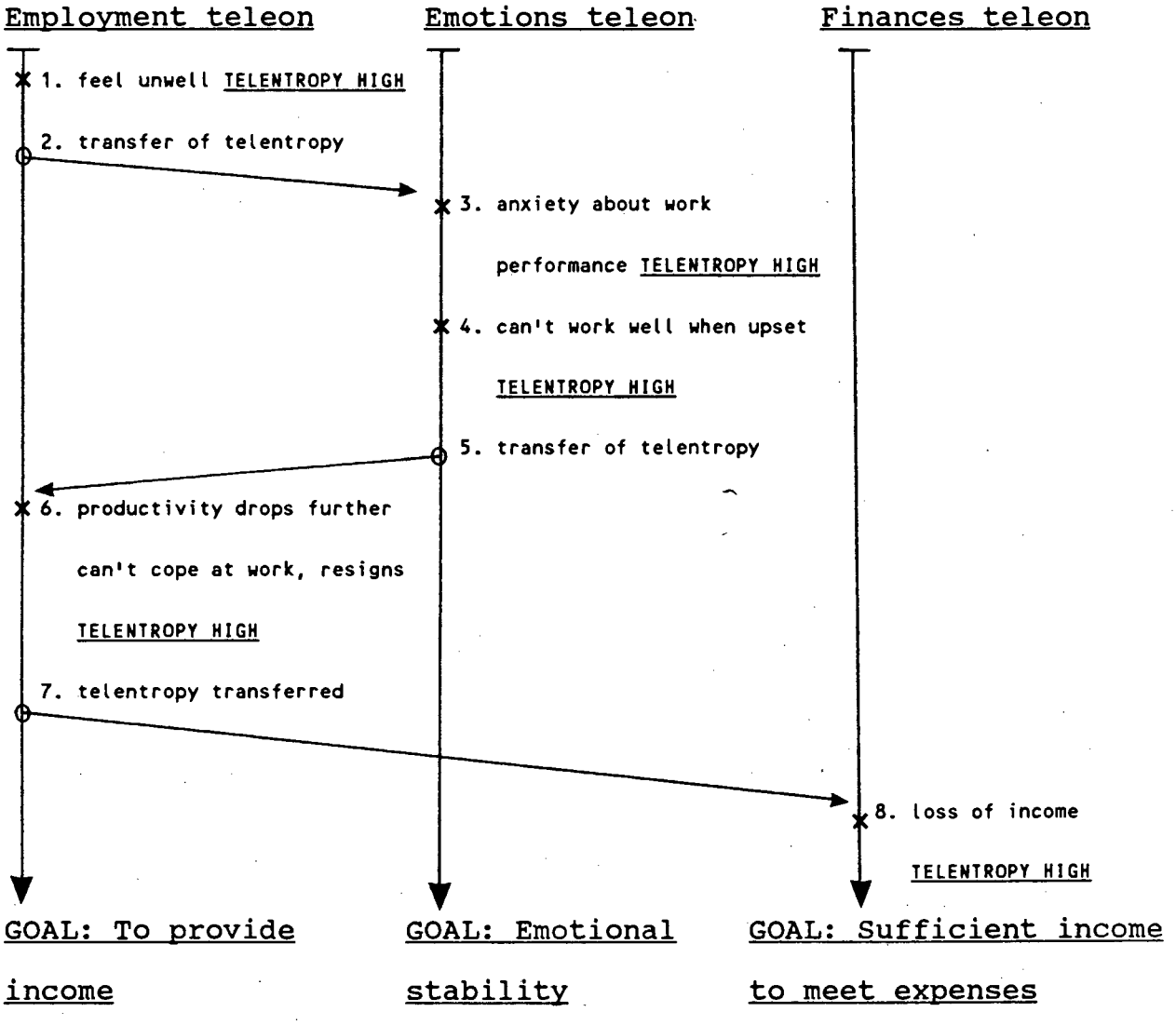
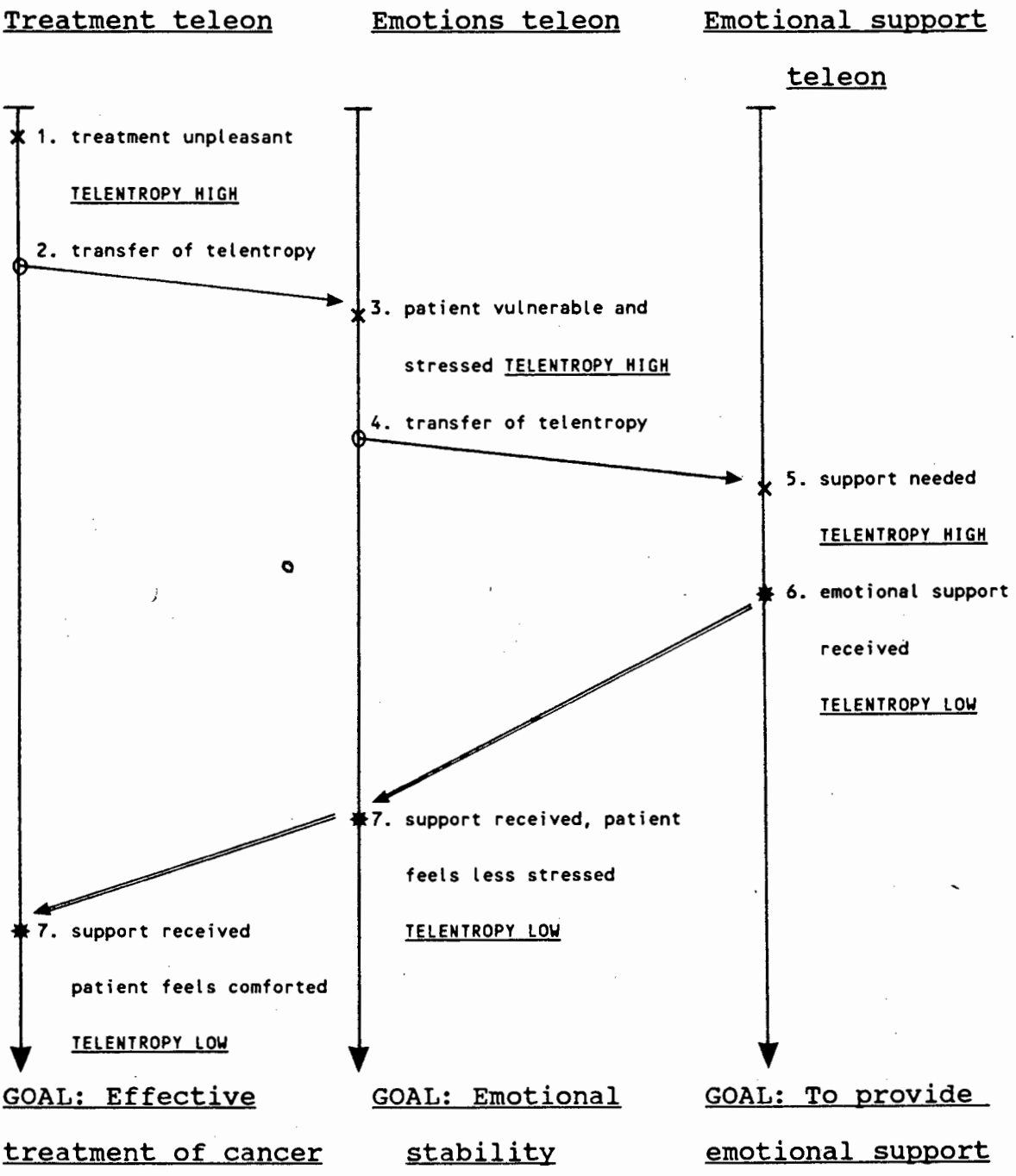


Figure 20: In this example (1) the patient has just finished a course of particularly unpleasant treatment resulting in high telentropy in the treatment teleon. (2) Telentropy is then transferred to the emotions teleon because the patient feels (3) vulnerable and stressed with telentropy high in the emotions teleon. (4) Telentropy is transferred to the emotional support teleon (5) because a need for support has been experienced. Telentropy is therefore high in the emotional support teleon and if this support is not provided, the telentropy will remain high. However, if the patient (6) receives support from family or friends the patient's stress can be relieved and telentopy will be lowered in the emotional support teleon. (7) Telentropy will also be reduced in the treatment and the emotions teleons, resulting in them having a high chance of reaching their respective goals.



seen to be the system that can best support the patient. Thus in moving away from the family, patients forfeit this very important buffer against cancer (Pilisuk & Parks, 1983; Suls, 1985) (see Figure 21). In some instances the family may be available to the patient but unable to give the patient the necessary support. This can happen when the equilibrium of the family system has been disrupted and family members are in need of support themselves (Vettese, 1981) (see Figure 22).

Once they are at major treatment centres patients may be emotionally isolated and very anxious. This anxiety can relate to the treatment to be received, the experience of being in a clinical environment, separation from family or many other problems. The relationship between the patient and the medical staff plays an important role in how the patient responds to the treatment environment (Anastasie, 1979). Many patients become withdrawn in this type of alien environment and feel overwhelmed and powerless to ask for help (Rabin & Wulf, 1985).(see Figure 23). Even though there are many problems for rural cancer patients associated with receiving adequate emotional support, it is by far the majority of patients in this study (i.e. 91% of rural patients and 83% of the urban control patients), that reported receiving the emotional support that they needed. In view of the fact that many rural patients have to leave their families for some time, it can only be suggested that the hospital staff, other patients and any other support systems that are available near to the treatment centre, play an important role in supporting the patients (Edwards,1987).

Emotional support of cancer patients has been identified as a critical issue in the management of cancer because it has been significantly correlated with a favourable response to treatment (Anastasie, 1979). Cancer is an extremely difficult disease to treat and any factors which may promote positive response to treatment should be strongly encouraged and promoted. Besides influencing response to treatment, a positive emotional state will enhance the

Figure 21: When patients (1) leave their families to travel to treatment centres telentropy is low in the transport to treatment teleon. (2) Telentropy will be high in the emotional teleon if this separation is distressing. (3) Telentropy is then transferred to the (4) emotional support teleon where telentropy will be high and will remain high if no support is forthcoming. If no support is received telentropy will also remain high in the emotions teleon resulting in the patient being distressed.

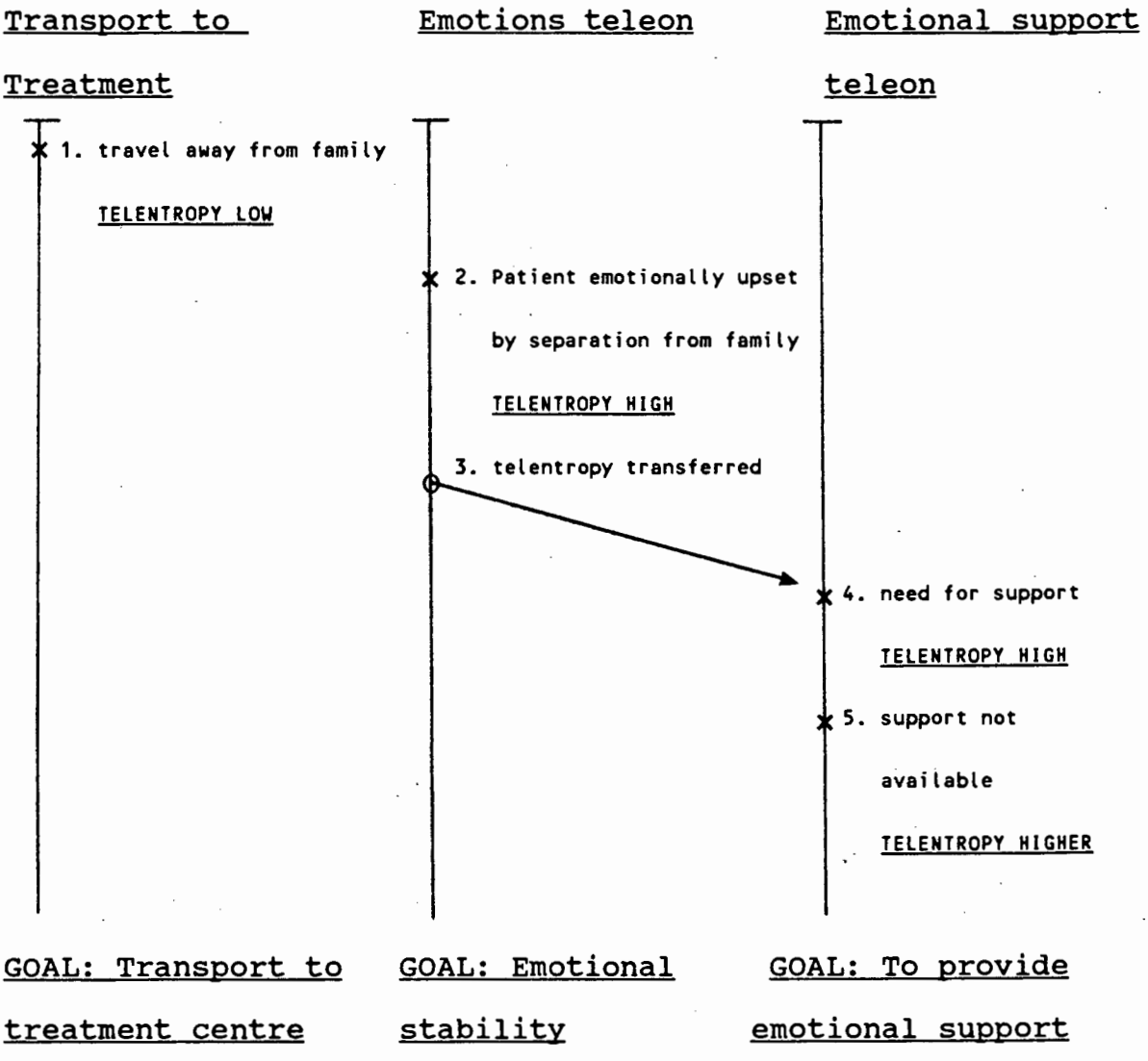


Figure 22: (1) When the patient feels distressed then high telentropy occurs in the emotions teleon. (2) The patient needs to transfer telentropy to the emotional support teleon, but as the family is disrupted, members feel unable to provide support. (3) Therefore due to the frustration in the emotions teleon there is a build-up of telentropy, (4) with the patient experiencing increasing anxiety and feelings of isolation.

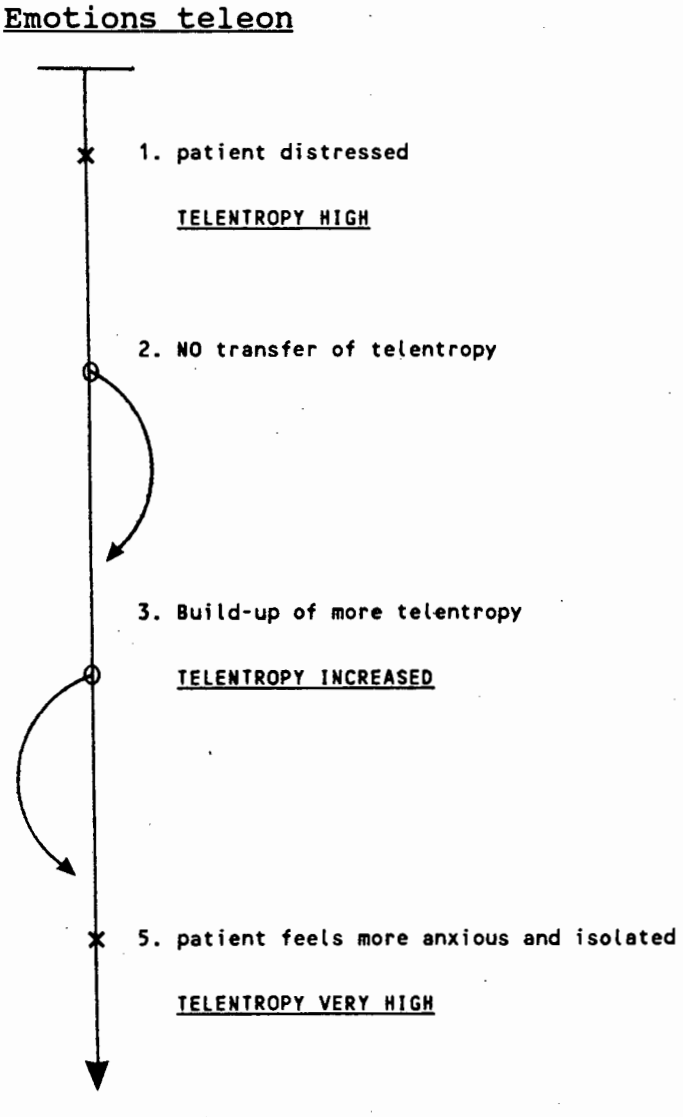
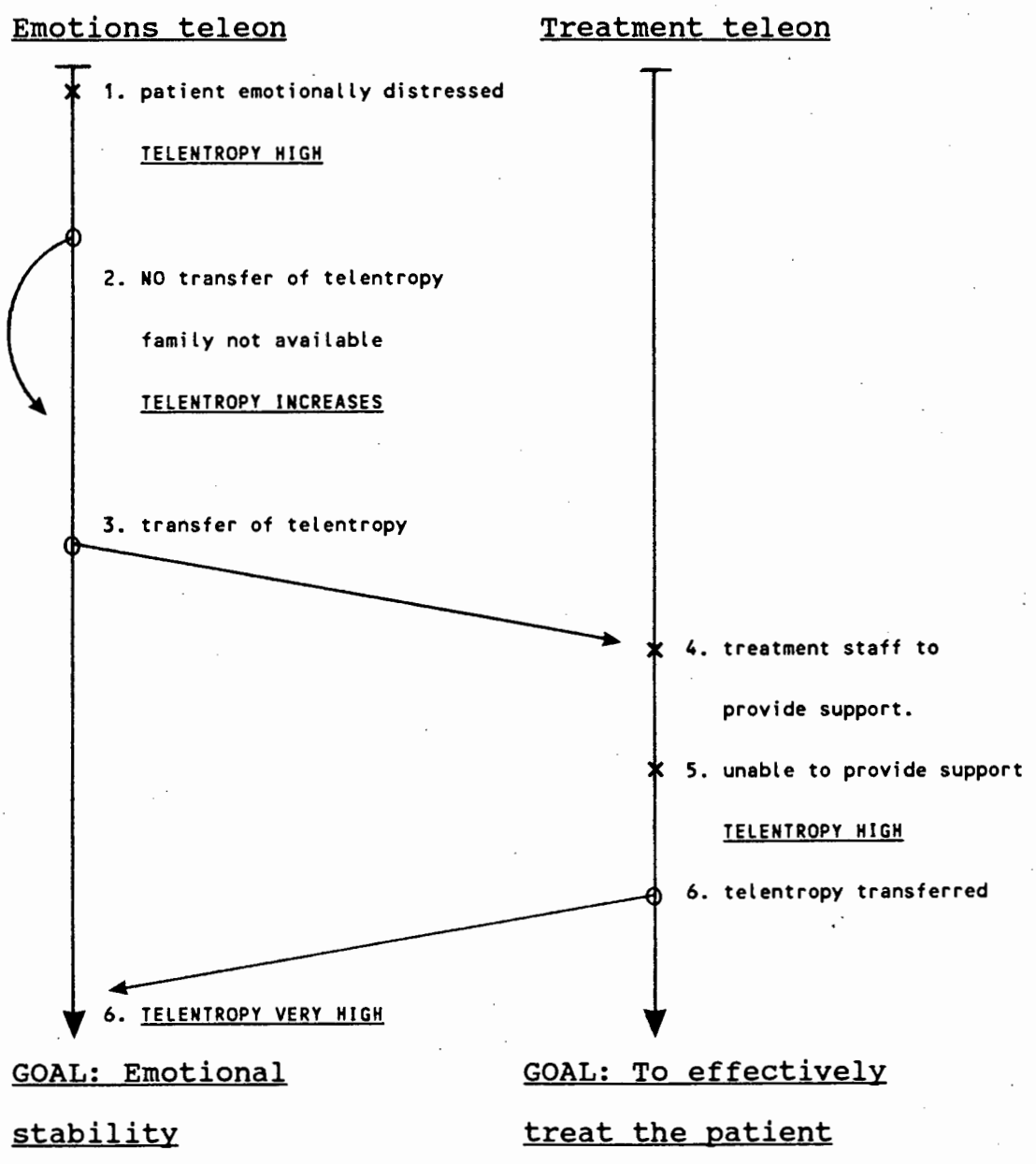


Figure 23: (1) When a patient is distressed, high telentropy is experienced in the emotions teleon. (2) If the emotions teleon is not able to transfer telentropy because the family are not available to support the patient, then telentropy increases. (3) Telentropy may be transferred to the treatment teleon for (4) treatment staff to give the patient support. (5) Should they be unable to provide the necessary support then not only will (6) more telentropy be transferred to the emotions teleon, but telentropy will remain high in the treatment teleon because the anxiety that patients experience may negatively effect their response to treatment.



quality of the patient's life. For cancer patients this is an urgent priority due to the life threatening nature of the disease.

7.3.9 Global Interpretation: The transfer of telentropy can be cyclical and interrelated and in this way reflects the interrelated nature of the processes of life. This means that telentropy can be transferred from one teleon to many others and back again to the original teleon. Telentropy can even be increased within a teleon if that teleon is unable to transfer telentropy, and keeps generating more telentropy within itself as the process of trying to reach it's goal becomes more and more frustrated. Teleons can transfer and receive telentropy in an interrelated, cyclical and dynamic way.

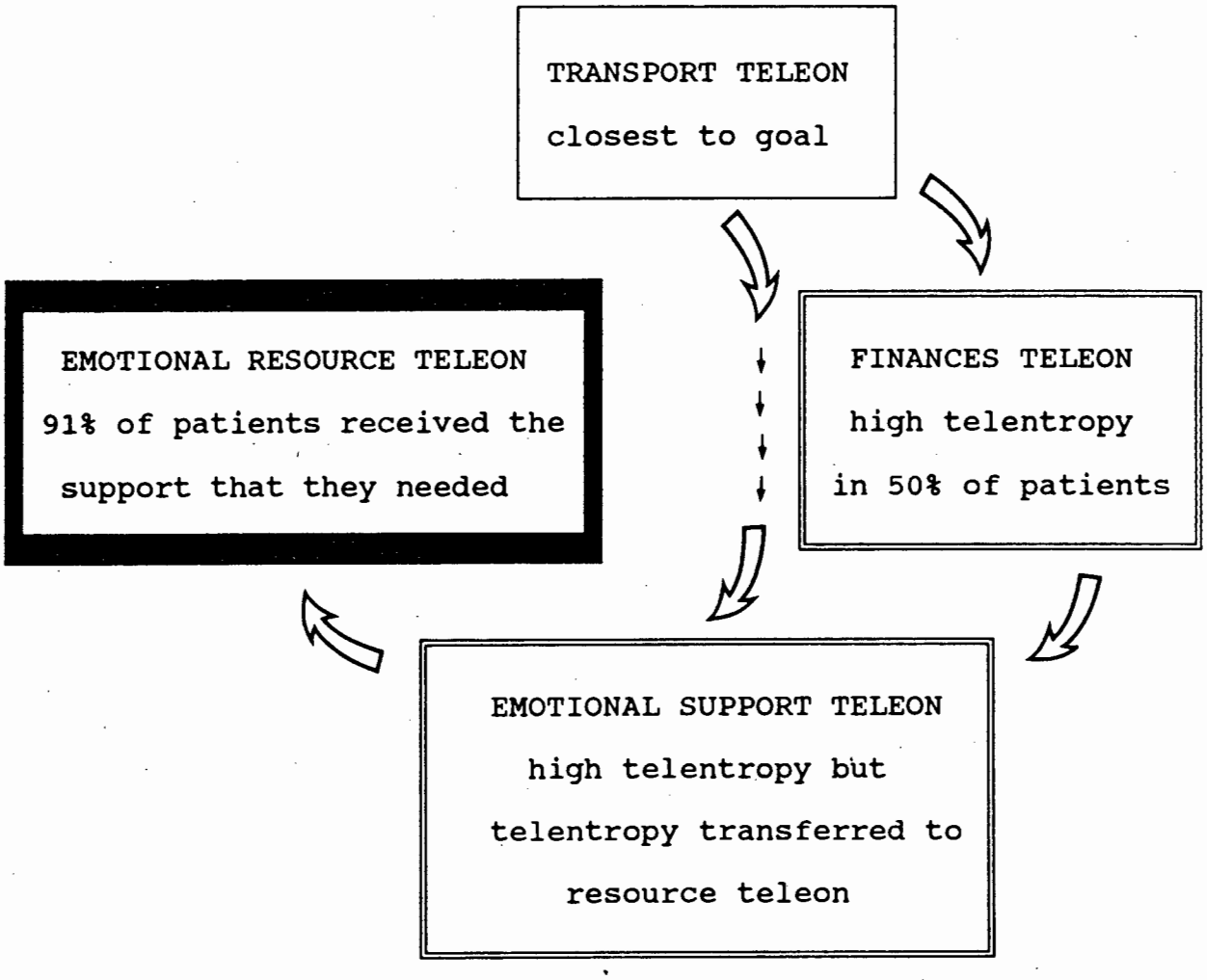
In summarising the transfer of telentropy in this study of rural cancer patients, it is suggested that the goal of the transport teleon is the most critical because of the immediate importance of treatment for cancer patients. The transport teleon, and to a lesser degree the finances teleon, is important in terms of enhancing the patients chances of survival. The emotional support teleon deals with the experience rather than the preservation of life.

The transport teleon appears to have its goals met at the expense of the emotional and the finances teleons. While it was possible for the finances teleon to transfer

telentropy in the direction of the transport teleon the

telentropy was transferred mainly from the transport to the finances teleon. This can be illustrated by the fact that many more patients reported financial rather than transport problems reflecting that telentropy was highest in the finances teleon. The emotional support teleon was the most vulnerable to the receipt of telentropy. It received telentropy from both the finances and the transport teleons. However, since a small proportion of the patients (9% rural patients and 17% urban control patients) in this study reported not receiving the emotional support that they required, telentropy must have been transferred from the emotional support teleon, which concentrated on support from the family, to alternative emotional resources (see Figure 24). Therefore the pattern of the transfer of telentropy in the rural cancer patient seemed to promote the chances of the transport teleon reaching its goal at the expense of the emotional support teleon. The finances teleon was important in that it absorbed telentropy from the transport teleon while at the same time transferred telentropy to the emotional support teleon. Because of all the telentropy that is received by the emotional support teleon, if the emotional support teleon cannot transfer this telentropy to supporting resources, excessive stress will be experienced in the teleon and therefore by patients. From the analysis of the transfer of telentropy between the transport, finances and emotional support teleons, it was clear that these teleons were very closely related but that many other teleons interacted with them.

Figure 24: This figure represents the global picture of the important teleons which influence the life of the rural cancer patient. The transport teleon has the best chance of reaching it's goal because it transfers much of it's telentropy to the finances and the emotional support teleons. The finances teleon transfers telentropy to the emotional support teleon which receives telentropy from both teleons. For most of the patients in this study, the emotional support teleon appeared to be successful in transfering telentropy to other resources thereby, managing to have low telentropy in the emotional support teleon.



## 7.4 CHAPTER SUMMARY

The Biomatrix Theory is a powerful tool for identifying the processes within and between systems. It provides a valuable framework for illustrating and explaining the complex relationships that can occur between processes in the lives of rural cancer patients. Rural cancer patients are surrounded by a complex and dynamic assortment of supradoublets of which the employment, cancer treatment and family supradoublets are the most important. Of the many subdoublets that make up the patient emotional state, the cancer in the body and the coping abilities are the most important.

The teleons which strive to satisfy the important needs of the doublet are the transport teleon, the finances teleon and the emotional support teleon. The transport teleon has the most chance of reaching it's goal because it transfers much of it's telentropy to the finances and emotional support teleons. The finances teleon has some chance of reaching it's goal because the patients who have telentropy in the finances can transfer some of this telentropy to the emotional support teleon. The emotional support teleon has the least chance of reaching it's goal because it receives telentropy from both the finances and the transport teleons.

Therefore in this study, the doublet had some of it's needs satisfied. The need to travel to the cancer treatment centre was generally satisfied. The need for income to be sufficient to meet expenses appeared to be met in 50% of

patients and the need to be emotionally supported and without undue stress was largely frustrated.

# CHAPTER 8: LIMITATIONS AND IMPLICATIONS

## 8.1 CHAPTER INTRODUCTION

In this chapter the limitations of this study will be discussed and recommendations for further research will be made. The major implications of the study will be outlined, with emphasis on future strategy for the effective and holistic management of rural cancer patients.

## 8.2 LIMITATIONS OF THE PRESENT STUDY

The researcher believes that the information presented has contributed to the understanding of the needs, problems and psychological stress experienced by rural cancer patients, nevertheless the limitations of this study are realized.

The information presented in this thesis also forms part of a National Cancer Association (SA) survey project which was undertaken by the author (Edwards, 1987). One of the main drawbacks of this work was that the aim of the survey project was to obtain a wide range of information to assist in the establishment of priorities for community planning for rural cancer patients (Alchin & Decharin, 1979). Because of the exploratory nature of the study, even though it may have been desirable in some instances, it was not practical to investigate psychological issues in greater depth. In addition to this some issues, which may have been relevant were excluded because they had not been reported in the literature or it was not within the aims of the study to include them. These issues include the influence of belief systems, sport and recreation on the lives of rural cancer patients.

Regarding the nature of the information that was collected, all of the information was of a self report nature. While the questionnaires used were found to be valid and reliable after repeated testing, the limitation of this technique is that when people are asked to assess themselves, they tend to report towards the middle point (Brewin, 1986).

Individual differences in the interpretation of concepts such as emotional support, financial difficulties and transport problems must also be considered as limitations when interpreting the results.

No information was collected on the diagnosis of the cancer patients who were interviewed. This was avoided because it can be a very sensitive issue and because patients seldom have accurate and reliable information about their diagnosis. This is a major drawback in that the type of cancer that patients have can seriously influence the problems that they experience.

Regardless of these methodological and practical limitations, it is felt that the findings of this study provide substantial pointers for further research in this field.

## 8.3 SUGGESTED AREAS FOR FURTHER RESEARCH

When one examines the scope and magnitude of the problem of cancer and what is known about it's costs and causes, the urgent need for psychosocial behavioural research into cancer prevention becomes clear (Fobair & Cordobac, 1982). Numerous cancers are preventable but action on the part of both society and individuals is necessary in order to accomplish the task.

Recommendations arising out of this study for further research are related to the empirical findings and the theoretical discussion surrounding these findings. Intensive investigation of emotional support, financial issues, employment and how it relates to cancer patients in general are important. Factors which were not investigated in this study but which are considered very important are the subject of patient's belief systems and the influence and attitude of society to cancer patients.

It would also be valuable to investigate the effect that the treatment modes have on the quality of life of rural

cancer patients, and which of the patient's concerns and anxieties relate directly to treatment. It is felt that further investigation into the many patients who live in non-urban areas is indicated. It is suggested that research be focussed on South African populations as most research on other rural populations (especially American rural populations) are not comparable with the unique historical, social, political and economic conditions which affect cancer patients in the rural areas of this country.

## 8.4 IMPLICATIONS OF THE STUDY

The essential aspect that separates rural cancer patients from their urban counterparts is their physical distance from cancer treatment centres. The problems associated with this factor are far reaching and, because of the many people who get cancer, has implications for the whole health care system.

This study highlights the importance of approaching cancer patients as emotional, social and physical wholes. To achieve such a holistic and co-ordinated approach, effective teamwork has to be undertaken by hospital staff and those of the local rural health care system (Allbrook, 1985; Brown & Kiaa, 1980; Engstrom, Anderson & Mortenson, 1983; Schreier & Dub, 1980). The effective co-ordination of this teamwork is essential if patient and family problems are to be dealt with systematically and comprehensively by the most appropriate combination of human resources (Engstrom et al., 1983).

The solutions to many problems relating to health care are financial and political (Schweitzer, 1982). While it may be an expensive and unrealistic disposal of resources to take most forms of cancer treatment and expertise to rural patients, mobile programmes and the training of rural staff can be undertaken to do home nursing, symptom management and the administration of certain types of treatment (Oberst, 1980; Hongladarom, 1983). Yates, Stewart, Hasler and Hockstin (1978) state that there are significant

emotional benefits from home nursing support and with the correct training the nurse is the logical caregiver to support the patient and the family (Oberst, 1980; Rinker, Rivers & Stewart, 1983; Yates, Mckegney & Kun, 1981). This would minimize the necessity for patients to travel long distances to receive treatment and care and would reduce the financial impact of cancer on both the patient and the central health care system.

Because of the wide variety of situations found in rural areas, planning of community care programmes should be individualized for each rural area dependent on the local availability of health care services (Committee on Cancer, 1955; Oberst, 1980; Rose et al., 1979; Young, 1986). Cancer care is a specialized area of expertise. The difficulty in obtaining specially trained medical staff in rural settings can make community based cancer care programmes difficult to implement (Beaton & Bourne, 1980; Huessy, 1972).

Since cancer is an illness which is most commonly found in older people it poses only a small threat to young people. Therefore, destructive lifestyles (eg. smoking) which can be causative agents in the development of cancer, are not discouraged in young people by the fear of cancer (Editorial, Cancer News, 1986). Because of the extreme suffering that cancer can cause, the negative attitude regarding early detection in the aged must be overcome. In addition education programmes should be established for young and old alike to approach the causes of cancer rather than their symptoms (Sternsward et al., 1986; Weinrich & Nussbaum, 1984).

## 8.5 SUMMARY

In summary, the personal, social and economic implications of cancer for rural patients involves much suffering and loss. While immediate problems must be urgently addressed to alleviate suffering, the implementation of a preventative approach to cancer control should be a

priority.

"The cause is hidden
but the result well known!"

Ovid (Fobair et al., 1982 p15)

REFERENCES

Alchin, E.W. & Decharin, P. (1979). An Ecosystem approach to community Development Research. In E. J. Blakely (Ed.), Community Development Research. New York: Human Sciences Ass.

Allbrook, D. (1985). Care of Patients with End Stage Cancer in Western Australia. Cancer, July, 9 (2), 60-68.

American Cancer Society. (1985). Can Surmount. American Cancer Society Inc. (Information Pamphlet)

Anastasi, A. (1979). Fields of Applied Psychology. Tokyo: Mc Graw-Hill Ltd.

Anderson, R.A. (1978). Stress Power. New York: Human Sciences Press.

Barton, S.N, Coombs, D.W. & Zakanycz, J.P. Rural Cancer Death. In J. Tache, H. Selye & S.B. Day. (Eds.), Cancer Stress and Death. New York: Plenum Medical Book Company, 1979, 233. (Book Abstract).

Beaton, G.R. & Bourne, D.E. (1980). Trends in the Distribution of Medical Manpower in South Africa. South African Medical Journal, May, 820.

Berlinski, D. (1976). On Systems Analysis. Massachusetts: MIT Press.

Bertalanffy, von L. (1968). General Systems Theory. New York: George Braziller.

Bloom, J.R. (1981). Cancer Care Providers. In P. Ahmed. (Ed.), Living and Dying with Cancer. New York: Elsevier North Holland Inc.

Bloom, J.R. (1982). Social Support Systens abd Cancer: A Conceptual View. In J.Cohen, J. Cullen & L.R Martin. (Eds.), Psychosocial Aspects of Cancer. New York: Raven Press.

Bluglass, K. (1986). Caring for the Family. In B.A. Stoll. (Ed.), Coping with Cancer Stress. Dordrecht: Nijhoff Publishers.

Blumberg, B.D., Ahmed, P., Flaherty, M., Lewis, J. & Shea, J. (1981). Living with Cancer. Living and Dying with Cancer. New York: Elsevier North Holland Inc.

Braddock, J.H., Crain, R.L., McPartland, J.M. & Daekins, R.L. (1985). How race effects job placement decisions: Results of a vignette experiment with a national sample of employers. Center for Social Organization of Schools Report, John Hopkins University, Report No 359, 1-14. (Abstract)

Bradshaw, E. & Harrington, J.S. (1975). The Changing Patttern of Cancer Mortality in South Africa, 1949-1969.

South African Medical Journal, May, 919-925.

Bradshaw, E. & Harrington, J.S. & McGlashan, N.D. (1983). Geographical Distribution of Lung and Stomach Cancers in South Africa, 1968-1972. South African Medical Journal, October, 655-663.

Breslow, L., Copley, G.D. & Lilienfeld, A.M. (1976). Epidemiologic and Biometric Manpower for Cancer: Report of a Meeting. American Journal of Epidemiology, 104 (2), 101-106. (Abstract)

Bresnick, E.R. (1981). A Holistic Approach to the Treatment of the Crisis of Infertility. Journal of Marital and Family Therapy, April 181-189.

Brewin, T.B. (1986). Quality of Survival. In B.A. Stoll. (Ed.), Coping with Cancer, Dordrecht: Nijhoff Publishers.

Brink, H. (1986). An Introduction to the Research Process. Nursing RSA, 1 (3), 22-23.

Brown, M.H. & Kiaa, M.E. (1980). Cancer Audit. Cancer Nursing, April, 1938-1944.

Bullock, A & Stallybrass, O. (1977). Fontana Dictionary of Modern Thought. Great Britain: Fontana Books.

Buncher, C.R. & Moomaw, C.J. (1984). A Methology to

determine completeness of population-based cancer incidence. Ohio: University of Cincinnati Medical Center.

Cain, L. (1979). A descriptive study analyzing coping methods instituted by patients who experience nausea and vomiting associated with chemotherapy treatment. Proceedings of the Fourth Annual Congress of the Oncology Nursing Society, May 17-19, New Orleans: Oncology Nursing Society, 1979. (Meeting Abstract)

Capra, F. (1987). The Turning Point. Glasgow: Fontana Paperbacks.

Cartwright, D.S. & Cartwright, C.I. (1971). Psychological Adjustment. Chicago: Rand McNally Psychology Series.

Clement-Jones, V. (1985). Cancer and Beyond. British Medical Journal, Vol 291, 12 Feb, 1021.

Cohen, F. (1979). Personality, Stress and the Development of physical illness. Health Psychology - a Handbook. California: Jossey-Bass Inc.

Cohen, J. (1982). Response of the Health Care System to the Psychosocial Aspects of Cancer. In J. Cohen, J. Cullen & L.R. Martin. (Eds.), Psychological Aspects of Cancer. New York: Raven Press.

Comazzi, A.M., Barbieri, A. & Tabiadon, D. (1981). Dynamica of Cancer Patients. Psychobiologic,

Psychophysiologic, Psychosomatic, and Psychosocial Aspects of Neoplastic Disease, 4th International Symposium, June 2-6 1981, Bressanone, Italy: European Working Group for Psychosomatic Cancer Research, 25. (Meeting Abstract)

Committee on Cancer. (1955). Manual for Cancer Registries and Cancer Clinical Activities. Illinois: Unpublished Report by the American College of Surgeons.

Conkling, V.K. Christ, G.H. & Fobair, P. (1986). Role of the social worker in cancer care. In R.J. McKenna & G.P. Murphy. (Eds.), Fundamentals of Surgical Oncology. New York: MacMillan Publishing Co.

Cooper, C.L. & Baglioni, A.J. (1988). A structural model approach toward the development of a theory of the link between stress and mental health. British Journal of Medical Psychology, 61, 87-102.

Cooper, C.L. & Crown, S. (1988). Stress and health: An introduction. British Journal of Medical Psychology, 61, 1-2.

Crown, S Book Reviews. (1985). British Journal of Medical Psychology, Vol 58, 395.

Cunningham, V.M. & Enck, R.E. (1981). Community Hospital Oncology Programme. 6th Annual Congress of the Oncology Nursing Society, May 4-6, Maryland, 104. (Abstract)

Editorial. (1983). Neigings in kanker, ras en omgewing. Suid Afrikaanse Mediese Journal, Vol 64, No 27, 1043-4.

Editorial. (1985). Nurse is the Pivot in Pain Management. Medical Chronicle, October, 8.

Editorial. (1986). Prevention is important. Cancer News, Vol 2, No 9, June 3.

Editorial. (1986). On the Record. Nursing Times, 10 December, 29-30.

Edstrom, S. & Miller, M.W. (1981). Preparing the family to care for the Cancer Patient at Home. Cancer Nursing, 4 (1), February, 49-52.

Edwards, L.B. (1987). Cancer Care Survey. Cape Town: South African National Cancer Association.

Elovaino, L., Hosti, L.R., Taskinen, P.J. & Viytukaubeb, A. (1977). The Finnish Cancer Patient. UICC Technical Report Series 26, 1977, 90-96.

Engstrom, P.F., Anderson, P.N. & Mortenson, L.E. (1982). Advances in cancer control. Proceedings of the joint meeting sponsored by the Association of American Cancer institutes and the Association of Community Cancer Centers, Washington D.C., March 4-7, 429-443.

Eysenck, H.J. (1984). Personality, stress and Lung

Cancer. In S. Rachman. (Eds.), Contributions to Medical Psychology Vol 3. London: Pergamon Press.

Eysenck, H.J. (1988). Personality Stress and Cancer. British Journal of Medical Psychology, 61, 57-75.

Fleiss, J.L. (1981). Statistical Methods for Rates and Proportions (2nd Edit.) New York: Wiley.

Fobair, P. & Cordobac, C.S. (1982). Scope and Magnitude of th Cancer Problem in Psychosocial Research. In J. Cohen, J.W. Cullen & L.R. Martin. (Eds.), Psychosoccial Aspects of Cancer. New York: Raven Press Books.

Fosset, M. (1986). Racial Occupational Inequality, 1940-1980: National & Regional trends. American Sociological Reviews, Vol 51, No. 3, June, 421-9.

Fowler, F.G. & Fowler, H.W. (1969). The Pocket Oxford Dictionary. London: Clarendon Press.

Fox, B.H. (1982). A Psychological Measure as a Predictor in Cancer. In Cohen, J.W. Cullen & L.R. Martin. (Eds.), Psychosocial Aspects of Cancer. New York: Raven Press Books.

Garfield, C.A. (1975). Consciousness Alteration and Fear of Death. The Journal of Transpersonal Psychology, Vol 7, 147-175.

Girdano, D.A. & Everly, G.S. (1979). Controlling Stress and Tension. New Jersey: Prentice-Hall Inc.

Goddard, J. (1986). Keeping the Aged where they belong,. Nursing RSA, Vol 1, No 10, 22-27.

Goodkin, K., Antonio, M.H. & Blaney, P.H. (1986). Stress and Hopelessness in the promotion of cervical intraepithelial neoplasia to invasive squamous cell carcinoma of the cervix. Journal of Psychosomatic Research, Vol 30 (1), 67-76.

Greenberg, M.R. (1984). Changing Cancer Mortality Patterns in the Rural United States. Rural Sociology, Vol 49 (1), 143-153.

Hartland, J.B. (1985). Setting up cancer support groups. Cancer Forum, Vol 9, No 2, July, 48-49.

Hawes, K.A. (1982). An Effective Economic Approach to Rehabilitation and Continuing Care: 4 years experience. 1982 ACCC/Progress in Cancer Control III Clinical Sessions, 8th National Meeting, March 4-7, Washington DC, Association of Community Cancer Centres. (Abstract)

Hongladarom, G.C. (1983). A Mobile Cancer Nursing Outreach Program. Cancer Nursing, 6 (1), 49-54.

Huessy, H.R. (1972). Tactics and Targets in the Rural Setting. In S.E. Golann & C. Eisdorfer. (Eds.), Handbook

of Community Mental Health. New York: Appleton Century Crofts.

Janis, I.L. (1969). Stress and Frustration. New York: Harcourt Brace Jovanovich Inc.

Janoski, M.L. & Schwartz, G.E. (1985). A Synchronous Systems Model for Health. American Behavioral Scientist, Vol 24, No 4, March/April, 468-485.

Jaros, G.G. & Cloete, A. (1987). Biomatrix: The Web of Life. World Futures, Vol 24, p215-236.

Jaros, G.G., Betts, J. & Cloete, A. (1988). Stress in Terms the Biomatrix. (In preparation for Publication), Department of Biomedical Engineering, University of Cape Town.

Jaros, G.G., Betts, J. & Johnson, D. (1988). The Family as a Doublet: An Analysis of Family Dynamics with the aid of the Biomatrix Framework. (in Press Journal of Family Process).

Johnston, L.C. (1986). Terminal illness: a psychosocial approach to the experience. PHD Dissertation, Boston University Graduate School. (Abstract)

Kalish, R. (1981). Coping with Death. In P. Ahmed. (Eds.), Living and Dying with Cancer. New York: Elsevier North Holland Inc.

Kalnins, I.V., Churchill, M.P. & Terry G.E. (1980). Concurrent stresses in families with a leukemia child. Journal of Pediatric Psychology, 5 (1), 81-92.

Kaplan H.I. & Sadock B.J. (1981). Modern Synopsis of Comprehensive Textbook of Psychiatry/III. Baltimore: Williams & Wilkins.

Katakis, C.D. (1988). Viewing Individuals and Families as purposeful Systems (In preparation for Publication 1988), Laboratory for the study of Human Relations.

Katakis, D. & Katakis, C.D. (1982). Teleonomic Entropy in Biosocial Systems. Behavioral Science, 27 (2), 118-124.

Katakis, C.D. & Thomassin, P. (1988). The Concept of Myth and the Properties of Living Systems. (In preparation for publication 1988). Laboratory for the study of Human Relations.

Kennedy, S., Kiecolt-Glaser, J. & Glaser, R. (1988). Immunological consequences of acute and chronic stressors. British Journal of Medical Psychology, 61, 77-85.

Kloppers, P.J., Van Staden D.A., Fehrsen J.P. & Van Der Walt, E. (1983). Suid Afrikaanse Mediese Tydskrif, Vol 64, Desember, 1062-3).

Kris J, (1981). Family Medicine and Holistic Health: An analytic Essay. Marraige and Family Review, Vol 4 (1/2), Spring/Summer, 73-80.

Kubler-Ross, E. (1969). On Death and Dying. New York: The Macmillian Company.

Kuchenhoff, J. (1981) Coping with a stoma; A comparative stufy of patients with rectal carcinoma or inflammatory bowl diseases. Psychotherapy and Psychosomatics, Vol 36 (2), 98-104. (Abstract)

Kulhavy, R. & Dee-Burnett, R. (1984). The 16 PF as a Guide to Predicting and Managing Stress. Institute for Personality and Ability Testing. Champaign, Illinois. (Technical Report 1).

Kulhavy, R. & Dee-Burnett, R. (1984). Construction and Validation of the Stress Inventory. Institute for Personality and Ability Testing. Champaign, Illinois. (Techninal Report 5).

Lancaster, J.D. (1986). Nausea in the Patient Receiving Chemotherapy. Nursing RSA, 3, 31.

Lane, T. (1986). Towards an Improved Need Theory. Behavioral Science, Vol 31, 205-216.

Le Shan, L. (1977). You Can Fight for Your Life. New York; M. Evans and Company.

Lazlo, E. (1983). Systems Science and World Order. Unitar New York: Pergamon Press.

Lazarus, R. (1982). Stress and Coping Factors. In J. Cohen, J.W. Cullen & L.R. Martin. (Eds.), Psychosomatic aspects of Cancer. New York: Raven Press.

Lee, M.S. (1986). Monitoring of Coping. In 1986 (Eds.). Coping with Cancer Stress, Dordrecht: Nijhoff Publishers.

Levenstein, S. (1980). The role of the G P in the care of the dying patient and his family. S.A. Family Practice, March, 11-15.

Levy, P. & Lemishow, S. (1980). Sampling for health professionals. California: Lifetime Learning Pub. Wadsworth Inc.

Lewis, W.A. (1985). Racial Conflict & Economic Development. Cambridge: Harvard University Press, 1985, 134. (Book Abstract)

Ley, P. (1977). Psychological Studies of doctor-patient communication. In S. Rachman (Eds.), Contributions to Medical Psychology. London; Pergamon Press.

Lilienfeld, R. (1978). The Rise Systems Theory. New York: John Wiley & Sons.

Mabogmje, O.A., Grundy, D.J. & Lawrie, L.H. (1980). Orchidectomy in a Rural African Population. Trans Research in Social Tropical Medicine and Hygiene, 74 (6), 749-751. (Abstract)

Maclennan, R., Muir, C., Steinitz, R. & Winkler, A. (1978). Cancer Registration and it's techniques. Lyon: IARC Scientific Publications.

Maisiak, R., Gams, R., Lee, E. & Jones, B. (1982). The Psychosocial Support Status of Elderly Cancer Patients. ACC/Progress in Cancer Control III Clinical Sessions, March 4-7 1982, Washington DC: Association of Community Cancer Centers, AD-1. (Meeting Abstract)

Mannes, R. (1982). The Oncologic Consultant. Psychologie Medicale, Vol 14 (14), 2143. (Abstract)

Mesarovic, M.D. & Takahara, Y. (1975). General Systems Theory: Mathematical Foundations. New York; Academic Press.

Miller, S. (1978). Experimental Design and Statistics. London: Methuen & Co. Ltd.

Miller, S.M. & Reissman, F. (1972). The Working Class Subculture: A New World View. In D.H. Wrong & H.L. Gracey. (Eds.), Readings in Introductory Sociology. New York: The MacMillian Co.

Milne, D., Burdett, C. & Becket, J. (1986). Assessing and reducing the stress and strain of Psychiatric nursing. Nursing Times, Vol 82, No 7, May, 59-62.

Mugford, S.K. & Gibson, D.M. (1986). Expressive Relationships and Well-being in an Aged Sample. Australian Journal on Ageing. August, 14-18.

Munnichs, J.M. (1986). Old age and cancer: Some psychological implications. 35th Oncology Meeting of the Nijmegen University Cancer Center, Vol 17 (2), 49-53. (Meeting Abstract)

Musci, E. (1985). Family concerns during Chemotherapy Treatment. Oncology Nursing Forum, 12 (2 Supplement), 67. (Abstract)

Nerenz, D.R. & Love, R.R. (1986). Types of Supportive Therapy. In B.A. Stoll. (Ed.), Coping with Cancer Stress. Dordrecht: Nijhoff Publishers.

Noakes, T. (1985). The Lesson Terry Taught Us. Executive Health, June, 11-14.

Norby, P.A. & Johnson J.L. (1985). We can weekend: A Program for Cancer Families. 3rd European Conference on Clinical Oncology and Cancer Nursing, June 16-20 1985, Stockholm Sweden. (Meeting Abstract)

Oberst, M.T. (1980). A Study in Cancer Control. Cancer Nursing, 3 (5), 384.

Panagis, D.M. (1982). Psychological Factors and Cancer Outcome. In J. Cohen, J.W. Cullin & L.R. Martin. (Eds.), Psychosocial Aspects of Cancer. New York: Raven Press.

Parrot, H. & Theeman, M. (1982). A Comprehensive Cancer Control Programme in Rural Maine. ACCC/Progress in Cancer Control, March 4-7, A-2. (Meeting Abstract)

Pilisuk, M. & Parks, S.H. (1983). Social Support and Family Stress. Marraige and Family Review, Vol 6(1-2), 137-156.

Pollard, B. (1985). The Dying Patient in a Teaching Hospital. Cancer Forum, Vol, No 2, 52-54.

Poynton, J.C. (1987). Smuts's Holism and Evolution Sixty Years on. Royal Society of South Africa, 46, part 3, June, p181-189.)

Rabin, D. & Wulf, T. (1985). The crisis moment in the doctor patient relationship. Medical Chronicle, October, 12.

Ramsey, M.M. & Hawes, K.A. (1982). Interagency/Interdisciplinary Team Development in a Rural Setting. The Seventh Annual Congress of the Oncology Nursing Society, April 23-25 1982, St Louis, Missouri:

Oncology Nursing Society, 99. (Abstract)

Raven, R.W. (1986). Rehabilitation and continuing care in cancer. England: Parthenon Publishers.

Rinker, M., Rivers, J. & Stewart, J.A. (1983). The role of Oncology Nurses in a Rural Environment. Oncology Nursing Society's 8th Annual Congress, May 18-21, Calafornia, 116. (Meeting Abstract)

Robbins, S.S. & Oliva, T.A. (1982). The Empirical Identification of Fifty-One Core General Systems Theory Vocabulary Components. Behavioral Science, Vol 27, 377-386.

Robertson, M.A. (1969). Clinical observations on Cancer Patterns. South African Medical Journal, 26 July, 915-913.

Rose, M.A., Kirkpatrick, M.K., Faber, D. & Pories, W.J. (1979). Care is Different in Rural Areas. American Association for Cancer Research, 20 (81). (Abstract)

Schain, W.S. (1981). Sexuality, Self-esteem and Cancer Management. In P. Ahmed. (Ed.), Living and Dying with Cancer. New York: Elsevier North Holland Inc.

Schmale, A.H. (1982). Stress as Factors in Health and Illness. In Cohen, J.W. Cullen, L.R. Martin. (Eds.), Psychosomatic Aspects of Cancer. New York: Raven Press.

Schreier, A. & Dub. B. (1980). The Doctor and the Social Worker. South African Medical Journal, 57 (23), June, 936.

Schweitzer, S.O. (1982). Economics of Cancer Prevention. In J. Cohen. J.W. Cullen & L.R. Martin. (Eds.), Psychological Aspects of Cancer. New York: Raven Press.

Searle, C. (1986). The Problem of establishing Elderly Cancer detection programmes in developing countries. Nursing RSA, Vol 1, No 10, 5 & 45.

Siegel, S. (1956). Non-parametric statistics for the Behavioural Sciences. London: McGraw-Hill.

Silberfarb, P.M. (1982). Research in Adaptation to Illness and Psychosocial Intervention. American Cancer Society, 50, November, 1921-1925.

Simonton, O.C. & Simonton, S.S. (1975). Belief Systems and the Management of the Emotional of Malignancy. Journal of Transpersonal Psychology, 7, 29-47.

Simpson, M.A. (1984). How to design and use Questionnaires in Research. Medical Teacher. 6 (4), 122-127.

*
Smedley, H., Sikora, K.& Robs,. (1985). Cancer. New York: Basil Blackwell Ltd.

* Sluzki, C.E. Process, Structure and World Views. Family Process. Vol 22, Dec 1983, 469-475.

South African Population Census. (1980). Pretoria: Department of Central Statistics.

Spiegel, M.R. (1972). Theory and Problems of Statistics. New York: McGraw-Hill.

Springer, J.R. (1985). The family with a chronically ill adult. Family Therapy Collections, No 13, 83-104. (Abstract)

Stjermsward, J., Stanley, K., Eddy, D., Tsechkoviski, M., Sobin, L., Koza, I. & Notaney, K.H. (1986). Cancer Control. Cancer Forum, Vol 10, No 3, November, 99-101.

Stoll, B.A. (1986). Faith only belongs in churches? In B.A. Stoll. (Ed.), Coping with Cancer Stress. Dordrecht: Nijhoff Publishers.

Stopher, P.R. & Meyburg, A.H. (1979). Survey Sampling and Multivariate Analysis for Social Scientists and Engineers. Lexington Books, Toronto.

Sullivan, A.L., Devine, R.J., Bowen-Thomas, J.E. & Tattersall, M.H.N. (1986). Cancer Patient's Needs. Cancer Forum, Vol 10, No 3, Nov, 92-94.

Suls, J. (1982). Social Support, Interpersonal Relations and Health: Benefits and Liabilities. In G.S. Saunders & J. Suls. (Eds.), Psychology of Health and Illness. New

Jersey: Lawrence Erlsbaum Ass.

Sutherland, J.W. (1975). Systems. New York: Van Nostrand Reinhold Co.

Swerdlow, M. & Stjensward, J. (1982). Cancer Pain Relief: An Urgent Problem. World Health Forum, 3 (3), 325-330. (Abstract)

Tach, J. (1979). Cancer, Stress and Death. New York: Plenum Medical Book Co. (Abstract)

Turk, D.C. & Kerns, R.D. (1985). A Transactional Model. The Family in Health and Illness. New York: John Wiley & Sons.

Vachon, M. (1984). Support Systems for the Health Professional. Nation Conference on Human Values. New York: American Cancer Society.

Vachon, M. (1986). Power and Control and the Person with cancer. Cancer Forum, Vol 10, No 2, July, 62-63.

Van Den Borne, H.W., Pruynj, F.A. & Meijk, D.E. (1986). Help Given by Fellow Patients. In B.A. Stoll (Ed.), Coping with Cancer Stress. Dordrecht: Nijhoff Publishers.

Vetesse, J. M. (1981). Family Stress and Meditation. In P. Ahmed. (Ed.), Living and Dying with Cancer. New

York: Elsevier North Holland Inc.

Viney, L., Clarke, A.M. & Benjamin, Y.N. (1986). A general systems approach to the patient, hospital staff, family and community. Behavioral Science, Vol 31, 239-253.

Viney, L. & Westbrook, M.T. (1987). Patterns of Anxiety in the Chronically Ill. British Journal of Medical Psychiatry, Vol 55, 87-95.

Webster, M. (1986a). Patients coping strategies. Nursing Times, 22 October, 3435.

Webster, M. (1986b). Easing Emotional Distress. Nursing Times, 29 October, 43-44.

Weinrich, S.P. & Nussbaum, J. (1984). Cancer in the elderly. Cancer Nursing, Dec, 475-482.

Weisman, A.D. (1979). Coping With Cancer. New York: McGraw Hill Book Co.

Weisman, A.D. (1986). Introduction. In B.A. Stoll. (Ed.), Coping with Cancer Stress. Dordrecht: Martinus Nijhof Publishers.

Wellish, D.K. & Yager, J. (1983). Is there a Cancer Prone Personality? South African Cancer Bulletin, 27(4), Oct-Dec, 125-135.

Wilson, B. (1984). Systems: Concepts, Methologies & Applications. Chichester: John Wiley & Sons.

Woodhall, C. (1986). A Family Concern. Nursing Times, 22 October, 43-44.

Woody, R.H & Springer, J.R. (1985). A Holistic Health Model for Family Therapy. Family Therapy Collections, 13, 36-45.

Wright, L.K. (1985). Life Threatening Illness. Journal of Psychosocial Nursing and Mental Health Services, Vol 23 (9), 7-11.

Wyndham, C.H. (1985). A Comparison of Mortality Rates from Cancer in White, Indian and Coloured Adults in 1970 and 1980. South African Medical Journal, 67, 4 May, 709-711.

Yates, J.W., McKegney, F.P. & Kun, L.E. (1981). Home Care for Terminal Cancer Patients. National Conference on Human Values and Cancer, April 23-25, A21. (Meeting Abstract)

Young, G (1986). Organizational Volunteers for the Rural Frail and Elderly. The Gerontologist, Vol 26, No 24, 342-344.

Zubrod, C.G. (1975). Successes in Cancer Treatment. Cancer, 39 (1), 267-270. (Abstract)

APPENDIX A

## PATIENT'S QUESTIONNAIRE

Patient's Town of Residence .....

Name .....

Age .....

Sex .....

Diagnosis (if available) .....

Race: .....

**IMPORTANT**: Please ensure that a code is filled into every block

Patient's Code 1 [ ][ ][ ] 3

Person Interviewed.
*Fill in the appropriate code*

Note If the patient is not available, only a primary care giver may be interviewed.

| | *Code* |
|---|---|
| Patient | *1* |
| Spouse | *2* |
| Child | *3* |
| Grandchild | *4* |
| Grandparent | *5* |
| Aunt/Uncle | *6* |
| Niece/Nephew | *7* |
| Friend | *8* |
| Mother/Father | *9* |
| Any other | *10* |

4 [ ][ ] 5

If any other please name

_____

# QUESTIONNAIRE

## A PRACTICAL FACTORS

### 1. Transport

1.1 Do you have to travel to Cape Town, Kimberley, Bloemfontein, Port Elizabeth or any other distant treatment centres. ☐ 6
*If YES score 1*
*If NO score 2*

1.2 If YES do you usually travel by:
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

1.2.1 Car ☐ 7

1.2.2 Train ☐ 8

1.2.3 Bus ☐ 9

1.2.4 Ambulance ☐ 10

1.2.5 Clinic/Hospital combi/bus ☐ 11

1.2.6 Any other ☐ 12

1.2.7 If any other, please name

_____

1.3 Is transport difficult for you to arrange? ☐ 13
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

1.4 Do you have to pay for the cost of your transport? [14]
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

1.5 If YES, approximately how much does it cost per return visit to hospital?
*Fill in the appropriate code*

| | | *Code* |
|---|---|---|
| 1.5.1 | Not applicable | *0* |
| 1.5.2 | Less than R5.00 | *1* |
| 1.5.3 | Between R5.00 & R15.00 | *2* |
| 1.5.4 | Between R15.00 & R25.00 | *3* |
| 1.5.5 | More than R25.00 | *4* |

[15]

1.6 Approximately how much time do you spend travelling to and from your most distant treatment centre?
*Fill in the appropriate code*

| | | *Code* |
|---|---|---|
| 1.6.1 | Not applicable | *0* |
| 1.6.2 | Less than 45 minutes. | *1* |
| 1.6.3 | Between 45 minutes and 2 hours. | *2* |
| 1.6.4 | Between 2 and 3 hours. | *3* |
| 1.6.5 | More than 3 hours. | *4* |

[16]

1.7 Do you have children who have to be cared for while you are at hospital?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ *17*

1.8 Do you have a problem in this regard?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ *18*

1.9 If YES please give details.

_____

_____

_____

## 2. Employment

2.1 Are you presently:-
*Fill in the appropriate code*

| | | *Code* |
|---|---|---|
| 2.1.1 | Employed (by self or others) | *1* |
| 2.1.2 | Retired | *2* |
| 2.1.3 | Unemployed | *3* |
| 2.1.4 | Housewife | *4* |
| 2.1.5 | Scholar | *5* |
| 2.1.6 | Student | *6* |
| 2.1.7 | Child | *7* |
| 2.1.8 | Resigned/Retrenched (not physically fit enough for work) | *8* |
| 2.1.9 | Any other | *9* |

☐ *19*

2.1.10 If any other, please name

_____

*Fill in the code as follows for questions 2.2 to 2.11 as well as for question 3.*

| | *Code* |
|---|---|
| *Does not Apply to me* | *0* |
| *Sometimes Applies to me* | *1* |
| *Frequently Applies to me* | *2* |

Attention Housewives only

Should housewives spend more than six hours engaged in activities related to the running of their home, they must consider themselves as employed by their husbands and should answer any questions relating to work/job/ employment with this in mind.

2.2 My current job makes great demands in terms of my performance. ☐ *20*

2.3 The job I hold has very little career potential for me. ☐ *21*

2.4 I have difficulty performing my present job to my satisfaction. ☐ *22*

2.5 Being able to satisfy supervisors is hard to do in my present job. ☐ *23*

2.6 The policies followed where I work tend to decrease my on-the-job performance. ☐ *24*

2.7 My work requires that I put in a lot of extra time outside regular hours. ☐ *25*

2.8 I have recently taken on a new job that demands much more of me than my last job. ☐ *26*

2.9 I should be paid more for the amount and type of work I perform on the job. ☐ 27

2.10 I am seriously thinking about leaving my present job for one with better working conditions. ☐ 28

2.11 My job really leaves me worn out at the end of the day. ☐ 29

3. Finances

3.1 At present, my personal finances are somewhat strained. ☐ 30

3.2 If YES is this as a result of your illness?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2* ☐ 31

## B MEDICAL AND NURSING PROBLEMS

4.1 Are all the medicines that you need at home easily available to you?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ 32

4.2 Give details of the problems that you have encountered in obtaining medicines.

_____

_____

_____

5.1 Have you experienced pain as a result of your illness?
*If YES score 1*
*If NO score 2*

☐ 33

5.2 When you are at home is your pain well controlled?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ 34

6.1 Have you experienced nausea as a result of your illness?
*If YES score 1*
*If NO score 2*

☐ 35

6.2 When you are not in hospital is your nausea well controlled?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ 36

7.1 During your illness have you had to spend a considerable amount of time in bed? ☐ 37
*If YES score 1*
*If NO score 2*

7.2 Have you developed any of the following complications as a result of your illness?
*If YES score 1*
*If NO score 2*

7.2.1 Bed Sores ☐ 38

7.2.2 Weakness ☐ 39

7.2.3 Boredom ☐ 40

7.2.4 Backache or Discomfort ☐ 41

7.2.5 Inability to wash properly ☐ 42

7.2.6 Loneliness ☐ 43

7.2.7 Constipation ☐ 44

7.2.8 Any other ☐ 45

7.2.9 If any other please give details

_____

8.1 Since your illness have you consulted with any of the following professional people outside of the hospital situation?
*If YES score 1*
*If NO score 2*

8.1.1 Doctor ☐ 46

8.1.2 Nurse ☐ 47

8.1.3 Dietician ☐ 48

8.1.4 Occupational Therapist ☐ 49

8.1.5 Physiotherapist ☐ 50

9.1 Have you needed any of the following equipment during your illness?
*If YES score 1*
*If NO score 2*

9.1.1 Wheel Chair ☐ 51

9.1.2 Commodes ☐ 52

9.1.3 Bed Pan ☐ 53

9.1.4 Urinal (bottle) ☐ 54

9.1.5 Sheep skin ☐ 55

9.1.6 Special Pillows ☐ 56

9.1.7 Walking stick or crutches ☐ 57

9.1.8 Any other ☐ 58

9.1.9 If any other, please name

_____

9.2 Were you able to get the equipment that you needed?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

☐ 59

9.3 Which person or organisation supplied you with the equipment that you needed?
*If NO COMMENT score 0*
*If ANY COMMENT score 1*

☐ 60

_____

_____

## C PATIENT SUPPORT NEEDS

*Fill in the code as follows for questions 10 to 28.*

| | *Code* |
|---|---|
| *Does not Apply to me* | *0* |
| *Sometimes Applies to me* | *1* |
| *Frequently Applies to me* | *2* |

10. I constantly seem to have problems getting along with members of my family. ☐ *61*

11. I prefer to spend less time with my friends now than I did before. ☐ *62*

12. The demands made on me by my family are very stressful. ☐ *63*

13. Many of the people I meet during the week seem to make me anxious and upset. ☐ *64*

14. I have heated arguments with at least one member of my family. ☐ *65*

15. Most nonjob relationships with other people are very demanding of my time and effort. ☐ *66*

16. My living situation is strained and tense. ☐ *67*

17. I have difficulty getting along with those whom I regard as socially senior to me. ☐ *68*

18. I wish that I could change my personal relationship with a member of my family. ☐ *69*

19. Because I am so busy, I prefer to keep my social contacts to a minimum. ☐ *70*

20. The type of life I presently lead interferes with my family activities. ☐ *71*

21. Lately, I have been losing my temper more often than usual. ☐ *72*

22. I have recently taken on a new family responsibility such as marriage, a new child, or a live-in. ☐ 73

23. At present, it would require a lot of effort on my part to make new friends. ☐ 74

24. I wish I could spend more time at home with my family. ☐ 75

25. Overall, I have trouble meeting the demands placed on me by each day's activities. ☐ 76

26. Recently, I have, or am planning to change my place or residence. ☐ 77

27. Just being pleasant to friends is getting very hard for me. ☐ 78

28. I get bored because I have too much leisure time on my hands. ☐ 79

29.1 Have you felt the need for any kind of emotional support during your illness? ☐ 80
*If YES score 1*
*If NO score 2*

29.2 Have you succeeded in gaining this support? ☐ 81
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

29.3 Which **ONE** of the following people was the **MOST** significant in providing you with this support?
*Score the appropriate code.*

| | | *Code* |
|---|---|---|
| 29.3.1 | Social Worker | *1* |
| 29.3.2 | Minister of Religion | *2* |
| 29.3.3 | Another patient | *3* |
| 29.3.4 | Friend | *4* |
| 29.3.5 | Psychologist | *5* |
| 29.3.6 | Psychiatrist | *6* |
| 29.3.7 | A member of your immediate family | *7* |
| 29.3.8 | Dietician | *8* |
| 29.3.9 | Physiotherapist | *9* |
| 29.3.10 | Community Nurse | *10* |
| 29.3.11 | A relative | *11* |
| 29.3.12 | Occupational Therapist | *12* |
| 29.3.13 | Hospital/Nursing Staff | *13* |
| 29.3.14 | Not applicable | *14* |
| 29.3.15 | Any other | *15* |

*82* [ ][ ] *83*

29.3.16 If any other, please name

_____

29.4 **IDEALLY** which **ONE** of the following people would be able to best give you the support that you need?
*Score the appropriate code*

| | | *Code* |
|---|---|---|
| 29.4.1 | Social Worker | *1* |
| 29.4.2 | Minister of Religion | *2* |
| 29.4.3 | Another patient | *3* |
| 29.4.4 | Friend | *4* |
| 29.4.5 | Psychologist | *5* |
| 29.4.6 | Psychiatrist | *6* |
| 29.4.7 | A member of your immediate family | *7* |
| 29.4.8 | Dietician | *8* |
| 29.4.9 | Physiotherapist | *9* |
| 29.4.10 | Community Nurse | *10* |
| 29.4.11 | A relative | *11* |
| 29.4.12 | Occupational Therapist | *12* |
| 29.4.13 | Hospital/Nursing Staff | *13* |
| 29.4.14 | Not applicable | *14* |
| 29.4.15 | Any other | *15* |

*84* ☐☐ *85*

29.4.16 If any other, please name

_____

29.5 Do you think that you would benefit from a group discussion of the problems that you have encountered since being ill? ☐ 86
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

30. Is there anything that you would like to mention regarding problems as a result of your illness that you have not had the opportunity to express in this interview? ☐ 87
*If NO COMMENT score 0*
*If ANY COMMENT score 1*

_____

_____

☐ 2 88

## APPENDIX B

USE PENCIL ONLY.

STUDENT NUMBER

### INSTRUCTIONS

The following 30 items ask that you evaluate each statement in terms of your own recent life experience. For each statement, please check one, and only one, of the three choices provided: "Frequently Applies to Me," "Sometimes Applies to Me," or "Does Not Apply to Me." Your response to each item is important in helping us develop a tailored program for you. Please don't skip any questions.

SCORING 2 1 0

EMPLOYMENT

FAMILY/SOCIAL

PERONAL.

| | Frequently Applies to Me | Sometimes Applies to Me | Does Not Apply to Me |
|---|---|---|---|
| My current job makes great demands in terms of my performance. | | | |
| I constantly seem to have problems getting along with members of my family. | | | |
| I prefer to spend less time with my friends now than I did before. | | | |
| The job I hold has very little career potential for me. | | | |
| The demands made on me by my family are very stressful. | | | |
| Many of the people I meet during the week tend to make me anxious and upset. | | | |
| I have difficulty performing my present job to my satisfaction. | | | |
| I have heated arguments with at least one member of my family. | | | |
| Most nonjob relationships with other people are very demanding of my time and effort. | | | |
| Being able to satisfy supervisors is hard to do in my present job. | | | |
| My living situation is strained and tense. | | | |
| I have difficulty getting along with those whom I regard as ~~my superiors~~ socially senior to me. | | | |
| The policies followed where I work tend to decrease my on-the-job performance. | | | |
| I wish that I could change my personal relationship with a member of my family. | | | |
| Because I am so busy, I prefer to keep my social contacts to a minimum. | | | |
| 16. My work requires that I put in a lot of extra time outside regular hours. | | | |
| 17. The type of life I presently lead interferes with my family activities. | | | |
| 18. Lately, I have been losing my temper more often than usual. | | | |
| 19. I have recently taken on a new job that demands much more of me than my last job. | | | |
| 20. I have recently taken on a new family responsibility such as marriage, a new child, or a live-in. | | | |
| 21. At present, it would require a lot of effort on my part to make new friends. | | | |
| 22. I should be paid more for the amount and type of work I perform on the job. | | | |
| 23. I wish I could spend more time at home with my family. | | | |
| 24. Overall, I have trouble meeting the demands placed on me by each day's activities. | | | |
| 25. I am seriously thinking about leaving my present job for one with better working conditions. | | | |
| 26. Recently, I have, or am planning to, change my place of residence. | | | |
| 27. Just being pleasant to friends is getting very hard for me. | | | |
| 28. My job really leaves me worn out at the end of the day. | | | |
| 29. At present, my personal finances are somewhat strained. | | | |
| 30. I get bored because I have too much leisure time on my hands. | | | |

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APPENDIX C

INSTITUTE FOR PERSONALITY AND ABILITY TESTING, INC.

April 6, 1984

Dr. Helgo Schomer
Lecturer, University of Cape Town
Department of Psychology
Rondebosch 7700
South Africa

Dear Dr. Schomer:

Thank you for your letter of March 14 regarding the Stress Evaluation Inventory.

There is no traditional test manual for the SEI, nor a hand scoring key. The scoring pattern is: all the Extremely Stressful responses receive 2 points; Moderately Stressful, 1 point; and Doesn't Stress me, 0 points. The items are assigned, in order, to Job, Family, Personal, Job, Family, Personal, etc.

Means and standard deviations for males and females in raw score terms are listed below.

Sincerely,

David H. Madsen, Ph. D.
Associate Director
Test Services Division

DHM:mh

| | Job | Family | Personal | Total |
|---|---|---|---|---|
| M | 5.83 (3.46) | 5.39 (4.00) | 3.87 (3.68) | 15.09 (8.74) |
| F | 6.96 (3.81) | 7.59 (4.16) | 4.96 (3.72) | 19.51 (9.32) |

Source: Stressbook

# APPENDX D

## A NOTE ON THE ORIGIN, RELIABILITY AND VALIDITY OF THE STRESS EVALUATION INVENTORY

### i) Origin

The Stress Evaluation Inventory (SEI) was originally compiled as an instrument to measure a broad set of responses which are a reflection of the "stress syndrome". The SEI has three primary 10 item scales reflecting the general content of employment stress, family stress and personal stress. The SEI takes approximately 15 minutes to complete with no time limit placed on testing. (Kulhavy, R. & Dee-Burnett, R., 1984: Tech. report 1).

### ii) Reliability

Scale reliabilities calculated as internal consistency co-efficients were excellent for the overall scale and generally quite good for the 10 item sub-scales. The sample that was originally used to compile the SEI comprised of 622 men and 205 women. Subjects were drawn in roughly equal proportions from established military, blue collar workers and white collar positions including a number of managers (Kulhavy, R. & Dee-Burnett, 1983: Tech. report 5).

### iii) Validity

As a check on the hypothesised structure of the SEI the item responses of the original 827 subjects previously described were factor analysed. From the final factor pattern it was concluded that from an interpretive point of view the employment, social and personal scales appeared to be largely undimensional and homogenous (Kulhavy, R. & Dee-Burnett, R., 1983: Tech. report 5).

# APPENDIX E

AGE: .....

SEX: .....

RACE: .....

Are you presently:-
*Fill in the appropriate code*

| | *Code* |
|---|---|
| Employed (by self or others) | *1* |
| Retired | *2* |
| Unemployed | *3* |
| Housewife | *4* |
| Scholar | *5* |
| Student | *6* |
| Child | *7* |
| Resigned/Retrenched (not physically fit enough for work) | *8* |
| Any other | *9* |

If any other, please name

_____

☐ *19*

| | Code |
|---|---|
| *Does not Apply to me* | *0* |
| *Sometimes Applies to me* | *1* |
| *Frequently Applies to me* | *2* |

Attention Housewives only

Should housewives spend more than six hours engaged in activities related to the running of their home, they must consider themselves as employed by their husbands and should answer any questions relating to work/job/ employment with this in mind.

My current job makes great demands in terms of my performance. ☐ *20*

The job I hold has very little career potential for me. ☐ *21*

I have difficulty performing my present job to my satisfaction. ☐ *22*

Being able to satisfy supervisors is hard to do in my present job. ☐ *23*

The policies followed where I work tend to decrease my on-the-job performance. ☐ *24*

My work requires that I put in a lot of extra time outside regular hours. ☐ *25*

I have recently taken on a new job that demands much more of me than my last job. ☐ *26*

I should be paid more for the amount and type of work I perform on the job. ☐ 27

I am seriously thinking about leaving my present job for one with better working conditions. ☐ 28

My job really leaves me worn out at the end of the day. ☐ 29

At present, my personal finances are somewhat strained. ☐ 30

If YES is this as a result of your illness?
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2* ☐ 31

| | *Code* |
|---|---|
| *Does not Apply to me* | *0* |
| *Sometimes Applies to me* | *1* |
| *Frequently Applies to me* | *2* |

I constantly seem to have problems getting along with members of my family. ☐ *61*

I prefer to spend less time with my friends now than I did before. ☐ *62*

The demands made on me by my family are very stressful. ☐ *63*

Many of the people I meet during the week seem to make me anxious and upset. ☐ *64*

I have heated arguments with at least one member of my family. ☐ *65*

Most nonjob relationships with other people are very demanding of my time and effort. ☐ *66*

My living situation is strained and tense. ☐ *67*

I have difficulty getting along with those whom I regard as socially senior to me. ☐ *68*

I wish that I could change my personal relationship with a member of my family. ☐ *69*

Because I am so busy, I prefer to keep my social contacts to a minimum. ☐ *70*

The type of life I presently lead interferes with my family activities. ☐ *71*

Lately, I have been losing my temper more often than usual. ☐ *72*

I have recently taken on a new family responsibility such as marriage, a new child, or a live-in. ☐ 73

At present, it would require a lot of effort on my part to make new friends. ☐ 74

I wish I could spend more time at home with my family. ☐ 75

Overall, I have trouble meeting the demands placed on me by each day's activities. ☐ 76

Recently, I have, or am planning to change my place or residence. ☐ 77

Just being pleasant to friends is getting very hard for me. ☐ 78

I get bored because I have too much leisure time on my hands. ☐ 79

Have you felt the need for any kind of emotional support during your illness? ☐ 80
*If YES score 1*
*If NO score 2*

Have you succeeded in gaining this support? ☐ 81
*If NOT APPLICABLE score 0*
*If YES score 1*
*If NO score 2*

| | Stratum | Cancer Mortality rate per 100 000 | Total Population | Sex | | Race | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Male | Female | White | Coloured | Black | Asians |
| Beaufort West | 1 | 131,6 | 27 600 | 13 120 | 14 480 | 5 900 | 18 560 | 3 040 | 100 |
| Calitzdorp | 2 | 117,9 | 6 500 | 2 900 | 3 600 | 1 320 | 5 040 | 140 | - |
| Calvinia | 1 | 116,2 | 18 360 | 8 620 | 9 740 | 3 900 | 14 100 | 360 | - |
| Carnarvon | 1 | 123,5 | 10 520 | 5 080 | 5 440 | 1 820 | 8 580 | 120 | - |
| Ceres | 2 | 64,3 | 36 780 | 19 280 | 17 500 | 5 780 | 28 840 | 2 140 | 20 |
| Clanwilliam | 2 | 110,8 | 24 960 | 13 220 | 11 740 | 4 360 | 19 720 | 860 | 20 |
| Fraserburg | 1 | 105,5 | 4 740 | 2 480 | 2 260 | 980 | 3 640 | 120 | - |
| George | 4 | 98 | 62 260 | 31 220 | 31 040 | 17 100 | 41 800 | 3 320 | 40 |
| Hermanus | 3 | 197 | 15 400 | 7 720 | 7 680 | 4 980 | 8 480 | 1 940 | - |
| Hopefield | 2 | 66,5 | 8 020 | 4 620 | 3 400 | 2 840 | 4 960 | 200 | 20 |
| Kenhardt | 1 | 79,9 | 11 680 | 5 720 | 5 960 | 2 240 | 8 700 | 740 | - |
| Montagu | 2 | 103,6 | 18 020 | 9 300 | 8 720 | 3 460 | 12 320 | 2 240 | - |
| Mossel Bay | 3 | 126,4 | 33 240 | 16 780 | 16 460 | 8 040 | 22 160 | 3 000 | 40 |
| Oudtshoorn | 4 | 81,4 | 61 460 | 31 360 | 30 100 | 15 840 | 42 120 | 3 500 | - |
| Prince Albert | 1 | 138 | 8 940 | 4 640 | 4 300 | 1 240 | 7 580 | 120 | - |
| Riversdale | 2 | 155,1 | 20 200 | 10 540 | 9 660 | 5 540 | 14 260 | 380 | 20 |
| Robertson | 3 | 99 | 27 940 | 14 480 | 13 460 | 5 320 | 20 500 | 2 100 | 20 |
| Tulbagh | 3 | 92,1 | 23 880 | 12 400 | 11 480 | 2 920 | 19 160 | 1 760 | 40 |
| Vanrhynsdorp | 1 | 120,1 | 11 280 | 5 580 | 5 800 | 2 780 | 8 460 | 140 | - |
| Vredenburg/ Saldanha | 5 | 70 | 31 920 | 18 180 | 13 740 | 8 520 | 20 400 | 2 960 | 40 |
| Vredendal | 2 | 128,4 | 22 840 | 11 280 | 11 560 | 4 980 | 17 300 | 540 | 20 |

TABLE OF CENSUS DATA FOR MAGISTERIAL DISTRICTS SAMPLED (SA CENSUS, 1980)