

THE EXPERIENCES OF DEATH AND DYING OF ZULU PATIENTS, THEIR  
FAMILIES AND CAREGIVERS

PATIENTS' CASE STUDY



LISSAH JOYCE THEMBA MTALANE

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## DEDICATION

This thesis is dedicated to the dying Black patients and their families in South Africa, and to the doctors and nurses that care for them (particularly those at Ngwelezana Hospital), and to my beloved husband, Baldwin.

## A DEATH SONG

Lay me down beneaf de willer in de grass  
What de branch'll go a-singin' as it pass  
An' w'en I's a-lyin' low,  
I Kin hyeah it as it go  
Singin', "Sleep, my honey, tek yo'-re' at las'"  
Lay me nigh to whah hit meks a little pool,  
An 'de watch stan's so quiet lak an' cool,  
Whah de little birds in spring  
Ust to come an' drink an' sing,  
An 'de chillen waded on dey way to school

Let me settle w'en my shouldahs draps dey load  
Nigh enough to hyeah 'de noises in 'de road;  
Fu' I t'ink de las' long res',  
Gwine to soothe me sperrit bes'  
If I's layin' 'mong 'de t'ings I's allus knowed.

Paul Lawrence Dunbar (1899)

(Black American)

(Kalish, 1977:95)

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## ABSTRACT

This thesis studies the impact of the terminal illness and awareness of undergoing the dying process and inevitable death, at the KwaZulu Government hospital Ngwelezana, at Empangeni in the Lower Umfolozi District. A case study, drawing both upon nursing and social anthropology, was conducted to establish the experiences of death and dying of Zulu patients, their families and caregivers. The basic trend reflected in the findings is the need to discuss dying with patients, the lack of skills and knowledge on the part of caregivers, lack of recognition of patients' cultural beliefs. The study does not claim to deal with a complete spectrum of the experiences of death and dying of all Zulus but is a meaningful and significant innovation into an unresearched area of patient care.

## DECLARATION

I declare that this thesis is my own, unaided work. It is being submitted for the Degree of Doctorate Social Sciences (Nursing) at the University of Natal, Durban. It has not been submitted before for any degree or examination at any other university.

Lissah Joyce Themba Mtalane

17 February 1989

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## CHAPTER 1

### PROBLEM STATEMENT

#### 1.1 INTRODUCTION

The concept and experiences of death and dying have been studied widely in the Western world. Research has delved into reactions of patients and their families to impending death and the dying process. It has also examined the attitudes and behaviour of nurses and doctors in dealing with dying patients and their families.

Much of the research already done in the West has brought about an awareness of the experiences and needs of dying patients and has resulted in improvements in medical and nursing care given to dying patients and to the support offered to their families. A significant outcome of such research has been the establishment of social support systems, the most outstanding being the Hospice Movement. The philosophy of the Hospice Movement is based on the recognition of the individual's worth - even in death and dying (Bohnet, 1982).

Various social scientists have researched the area of death and dying in South Africa. These studies have however, been undertaken in the White population. (Joubert, 1982; Lasker, 1981; Moore, 1981; Smith, 1981; de Villiers, 1982); and the question of whether the experiences of death and dying as described in them are relevant to Black patients cannot be avoided. The generalizability of some of their findings is indeed questioned here. While the findings reported in this thesis and its recommendations are based on research undertaken specifically for the purpose, many of the general insights came from my experience of nursing dying patients since 1958. As a

Zulu myself, my sympathetic awareness of the implications of Zulu cultural beliefs and Zulu cultural expectations has grown as I have seen and experienced the very real problems which Zulu patients and their families experience when interacting with hospital personnel who are either ignorant or dismissive of their point of view. This thesis is an attempt to address the problems of different cultural perspectives on dying and to redress the existing situation by suggesting that a creative solution is possible (and indeed necessary) to the confrontation of divergent cultural beliefs in the South African medical arena.

In nursing theory emphasis is placed on providing care to meet the needs of patients, including that of dying patients. The Roper model of activities of daily living, and the nursing process model adopted in South Africa, are examples of the nursing models that incorporate this aspect into the role of the nurse (Roper, 1985; S.A. Nursing Council, 1985; Searle, 1986). In its resistance to euthanasia, nursing ethics hold that a patient should be cared for and assisted to a peaceful, painless death (Searle, 1986). My experience in nursing Zulu patients has confirmed this view.

As I have achieved seniority in the nursing hierarchy, it has become clear to me, however, that the care of the dying is an extremely complex issue. It involves a large and diverse interacting group - the patient, his or her family, and the caring team which consists mainly of doctors and nurses. As a nurse administrator on ward inspections, I have become increasingly sensitive to the unmet needs of the dying patients. These require, I believe, an improved nursing

approach to the dying patients. A point of special motivation for this study was in 1985, when I became aware of the changed and improved communication between patient and doctor, due to better medical staffing levels which allowed for a team approach - a team of three doctors to a group of patients. The doctors' approach to terminally ill patients was now to inform them about their diagnosis and prognosis. This created a climate of awareness of impending death for the patient, family and the caregivers. Undertaking research to describe the experiences of the three parties involved became an essential commitment in order to improve nursing approaches.

## 1.2 RESEARCH QUESTION

In summary, then, the research question posed in this thesis is "What are the experiences of death and dying of Zulu patients, their families and the caregivers involved?"

## 1.3 IMPORTANCE OF THE STUDY

Death and dying is a life stage which is a difficult agonising personal experience for both patient and family and about which knowledge is needed for good care.

Zulu experiences of death and dying are an under-researched area, and hence, the motivation for this study.

#### 1.4 THESIS OUTLINE

Chapter two of this study is the literature survey on death and dying which gives the medical context. Chapter three focusses on Zulu cultural views of death and dying because the study is of Zulu patients and their families.

In chapter four, I recount some of my own experiences of nursing dying patients since 1958. I have cast this chapter in the form of a short autobiography because I feel that this illustrates extremely well not only many of the points raised in this thesis, but also takes the Western reader into the world of a contemporary Zulu woman and Zulu nurses. The autobiographical chapter may appear at first sight to be not only unusual, but rightly subjective. I believe, however, that it is an excellent vehicle for exploring the socio-cultural, as opposed to the medical context. Since it is largely in respect to socio-cultural factors that I believe that care of Zulu dying patients needs revision, this section together with chapter three, forms the foundation for the rest of the study.

The research method for the study is outlined in chapter five, and chapter six presents the ten case studies in narrative form. This is followed by the cross-analysis of findings of the ten case studies in chapter seven. The last chapter gives conclusions and recommendations to the study.

## LITERATURE SURVEY : DEATH AND DYING IN MEDICAL CONTEXT

## 2.1 INTRODUCTION

Death and dying are phenomenon which people experience differently and about which they have different attitudes and beliefs. Culture, religion and the process of socialisation in different societies contribute to or form the basis of an individual's perception and reaction to death and dying (Feigenberg, 1982). The science of death and dying is referred to as thanatology, and has become an important area of study in human sciences, particularly in psychology, sociology and anthropology. Philosophy and theology have, however, also delved in this topic (Feifel, 1977).

Dying is often regarded as a phase of the life span. The dying process is as natural as any other phase of life, and as natural as childbirth. A dying person may be suffering from a physical or mental condition, but the dying process is not automatically equivalent to personal pathology. In advanced age, inner infirmity and outer depletion may combine to make the margin between living and dying almost arbitrary (Weisman & Kastenbaum, 1968).

## 2.2 APPROACHES TO DEATH AND DYING

## 2.2.1 Death as a Phase of Life

Death may be seen as a phase of life. It is often perceived in its relationship to life and what is to happen after life. Life up to

this stage is associated with the individual's social function, his activity in the network of emotional relationships, his capability of being in control of himself, his ties in his occupation, family, and community but all of these decline or cease when the dying phase sets in (Feigenberg, 1980). Feifel (1977) said that death comes to the living, and not to the dead. Dying being a phase of life, incorporates a time concept, relating past life, the present state of dying, and the future. It is during this process that the person looks back at his past life. Memories, feelings and thoughts about the past become the central aspect of dying. The mind is consumed with dreams, fears, and hopes about death.

At this phase of life, the person develops a certain perception of the self. His body becomes foreign, and his pain often governs his mind and body. He looks at his body recognising marks of the duties it performed, such as scars, bruises, hard soles of feet. This may bring a sense of accomplishment, sadness or feelings of guilt. He sees his body declining in size or stature. All this goes on in the patient's mind, and all the caregivers can observe is the behaviour and reactions it leads to (van der Berg, 1980).

### 2.2.2 Death as a Process of Biological Degeneration

Dying is a process of progressive decline and irreversible degeneration of the biological functioning of the body. It starts at a certain point in time when the dying phase sets in, and ends when

the person dies. The duration of dying varies from seconds, minutes, hours, days, months and years (Sudnow, 1967). Medically a person may be sick for years before he starts dying. In other words, dying is when a person is in a particular phase of a disease, which usually leads to death (Feigenberg, 1980). In medicine this is referred to as the terminal illness syndrome.

Terminal illness is usually characterised by a group of physical and psychosocial symptoms, namely pain, anorexia, nausea, vomiting, dyspnoea, dysphagia, incontinence, lethargy and weakness, cachexia, fungating wounds and anxiety and insomnia (Tiffany, 1978). That means that there is severe physical deterioration, metabolic changes, which tend to obscure the individual's existence as a person (Weisman, 1982).

*Advancing & terminal illness*

The onset of the terminal phase of illness is not precise. We may say, it begins when the dying person begins to withdraw into himself in response to internal body signals (Pattison, 1977). It is marked by both physical withdrawal, and subtle signs of emotional disorganisation (Lieberman, 1965).

As the terminal stage progresses there is loss of muscle tone, cessation of peristalsis, slowing of blood circulation, laboured respiration, and loss of senses. Loss of muscle tone is often manifested in the inability to control defecation and urination. It

also results in difficulty in maintaining posture, dysphagia, and accumulation of mucus in the throat causing gurgling sound. The patient has no desire to eat or drink, and this results in generalised weakness and dehydration. Due to lack of peristalsis flatus accumulates in the stomach and intestines, and distension of the abdomen and nausea occurs (du Gas, 1983).

Just as it is impossible to state categorically the exact time of the onset of dying, it is impossible to state with precision the prognosis of when it will end. The nature of the particular disease, pathology involved, determines the course and the speed of the irreversible degeneration of the body function (Kastenbaum, 1981).

Together with the physical/biological view of dying, comes a physical definition of death. Since the late 1950's and in the 1960's the concept of cerebral death developed and became universally accepted. This went along with the concept that persistence of normal life is dependent upon integrity of that part of the nervous system which controls the vital function, and upon the integrity of vital organs themselves (Tonybee, 1968).

The medical definition of death by Ramsey is that "death means the permanent disintegration and cessation of the spontaneous and integrated functions of intake distribution, and utilisation of oxygen ... (which) may happen within the system beginning with the

destruction of brain's utilisation of oxygen, or it may happen by respiration blockage or by cardiac arrest. The destruction of one leads finally to the abolition of the other of these vital functions" (Margolis, 1975).

In this physical view we see a professional obligation on the caregivers to sustain the physical functioning of the body. We see a professional responsibility of improving means and skills in fulfilling societal expectations.

### 3.2.3 Philosophical Views

Philosophers have always been interested in death and questions about life and its meaning. Philosophy holds a concept of a person as involving embodied existence. In this existential view, philosophers label death as absurd. They feel that the reason to live, the ultimate justification and value for life, is living itself. Impending death challenges traditional values and their religious supports, and has left many facing an existential dilemma of providing purpose to keep on living. This results in a panicky tenacity to hold on to one's life. As a result modern Western medicine has become the servant of a culture devoted to the preservation of life at all costs. In modern medicine death is therefore viewed as an intrusion into medical scientific quest for eternal existence (Pattison, 1977).

Western  
culture  
NS

Dying is a process which comes within a person, and that is what makes a difference between dying and being killed. The dying process may be slow or quick. From symptoms it may be said a person is dying, but symptoms may be misleading. Therefore, dying is not symptoms, but it is a process. In the man's mind it is asymmetrical with birth and death. This attitude explains the reason for the attraction of myths of the future consummation of history. This in turn links with a sense of destiny for all of us (Tonybee, 1968).

The process of dying can be a mode of expression of a person's character. Dying can be met with admiration if a man compasses it with dignity and serenity. To die courageously, is facing death in a certain style (Tonnybee, 1968).

Regarding the concept of existentialism, the philosophers find the concept of disembodied personal existence in another world contradictory. Schopenhauer, a philosopher, said that the prevalence of a belief in immortality is a token of the awful fear of death. On the other hand, fear of death was the beginning of philosophical view of existentialism and the final cause of religion according to Durant (1952).

#### 2.2.4 Religious Views

The definition of religion incorporates belief in the existence of a divine, superhuman ruling power that must be worshipped and obeyed (Ellis, 1980). It is described as a coping mechanism, a source of

strength, peace, comfort, security, stability, emotional support, and a personal meaning system for dealing with questions of identity, purpose, relationship to the universe, a source of hope, a fellowship of believers connected to each other by the shared events of their lives; a framework for good living and a conscious pursuit of any object the person holds as supreme (Brady, 1979 ; Malinowski, 1948).

Various religions have different perceptions of God. God is whatever the individual values most highly, and which provides focus and purpose (Ellis, 1980). God is seen to some as fearful, punitive master, and to some as loving, personal presence. Others perceive God as a specific active force, a cosmic intelligence. The belief in God, then becomes an active force that unifies humanity, families, societies (Peck, 1978). Religion is therefore seen as an activity and its associated beliefs, values and bonds provide a unifying or integrating force in the person's life.

All formal religions help people in their search for inspiration and insight when they are forced to face great existential questions provoked by suffering (Becker, 1973). In the face of death and dying religion provides comfort, because it has a defined purpose and meaning for humanity, such as, life after death.

Vernon (1980) in the sociology of death concluded that, the very origin and development of religion lies in the man's concern with

death. Malinowski (1948) and James (1950) concluded that the spiritual interpretation of death developed by primitive man, provided the foundation from which was developed the complex religious configurations involving the various other types of spiritual phenomena. ✓

Malinowski also concluded that religion counteracts the centrifugal forces of fear, dismay and demoralisation and provides the most powerful means of reintegration of the groups shaken solidarity and of the re-establishment of its morale.

Summer and Keller (1972) as quoted by Vernon (1970), endorse the Malinowski's theory that man developed the concepts of an afterlife and a soul to assuage the terror that he experienced in the face of the unexplainable, seemingly inevitable fact of death. The afterlife is perceived as being more attractive than this life and it is longed for.

Diggory - Rothman (Vernon, 1970) study of death distinguished different types of death fears. He found out that religious affiliation was related to the type and intensity of such fears. The rank order of religious groups from high to low along an intensity continuum for such fear was as follows - no religion, Jewish, Protestant, Catholic.

Marcuse (1959) concluded that in view of the fact that death is inevitable, fear of death is, therefore, a fear of a real omnipotent danger. In their research, Kalish (1977) and Kubler (1975) indicate that the fear of death is least among the deeply religious patients. This is so because their faith and love for God, they feel secure in the face of death.

Research indicates that there are religions that firmly believe in life after death; and those that believe that human life and intelligence are random biological events. The latter belief equates man to an animal. These two groups of believers are said to be equally secure in the face of death. It is the unsure, in between group which has the most difficulty in accepting their personal finitude (Bohnet, 1982).

Those who believe in life after death, perceive death and dying as a transition or transformation from one state of existence to another. In that sense the dead have "gone to sleep" and would awaken at the end of the world to meet God in heaven (du Bois, 1980; Yosef & Regensberg, 1986; Shanley, 1982, McCarthy, 1980). This union with God in heaven is seen as a reward for good religious life during lifetime. The religious system is therefore so organised and characterised by the adherence to prescribed beliefs, norms, ethical codes, rituals, and practices (Munley, 1983; Henderson, 1978).

Christianity purports that there is life after death. Roman Catholics, Protestants and Jews believe that death marks the beginning of an afterlife with God. Some being convinced that this existence is everlasting and will hold far greater joy and peace than life on earth. With such a philosophy then, the purpose of dying is to allow progression from life on earth to the afterlife (Hinton, 1974).

Belief in afterlife is pancultural, for example, for the Buddhists, Scandinavians, pre-Christian Greeks, Persians and the Western world. The archeologists have described previous cultures after studying their grave sites, that provision for the physical needs of dead, indicated their belief in afterlife (Carter, 1981). The anthropologists believe that the objects found in ancient graves, were meant to be useful to the deceased wherever they were going (Bohnet, 1982). Also the belief in afterlife indicates the promise of an eternal life reward in heaven. This connotes a belief that the deceased pass to a state of victory in the afterlife. A belief also exists that the dead are subjected to ordeals of one type or another prior to reaching an exalted state in the afterlife.

Another anthropologist, Cohen (1968) concluded that every society possessed the belief that the individual has a non-physical or spiritual life in addition to the physical one.

Passmore (1970) quotes Plato as saying that the soul "most closely

resembles the divine and immortal, intelligible and uniform and indissoluble, and ever-unchangeable, while the body most resembles the human and mortal, the unintellectual and dissoluble and ceaselessly changing." Each individual possessed these perfections. In this theory one sees a different philosophical view that subscribes to the concept of disembodied existence.

According to Juan's analysis, men actually believe themselves to be immortal. The individual is reminded of his own death when a death occurs (Margolis, 1975).

✓ Immortality, according to Kalish (1977) is the most essential concept of all religions. Worship of ancestors, who are thought to be still "around" is some form of expressing immortality. The so called primitive religions also seem to centre on the expectation of some kind of further existence (Lewis, 1978).

✓ Formal religions have certain religious or spiritual rituals and practices which essential spiritual support for the dying, and the bereaved family, through their caring actions. They also give sustaining power, and help people relate themselves to the eternal (Holland, 1975; Pumphrey, 1982).

### 2.3 REACTIONS TO IMPENDING DEATH

During the phase of terminal illness, the patient might discover the

seriousness of his illness. The message of death enters his existence, and spells out that life is at its end. Tonybee (1968) stated that dying is predicated of the person himself, as though the process originates from within himself. It is this that makes death a personal experience for each person and therefore each person reacts differently to dying.

A dying person encounters a mesh of feelings and situations with anxiety, depression, revolt and resignation predominating. The patient is in conflict with his surroundings, and the reality of life is lost (van den Berg, 1980). He focusses on visible bodily changes and impaired functioning. This gradual loss of body image causes a lot of concern and emotional suffering. These changes could be marked weight loss, mutilating surgical procedures, such as amputation of a leg, a mastectomy or colostomy, to mention a few.

Hinton (1963) in his studies established that there is decrease in anxiety when death is seen as inevitable, but the person becomes more depressed, which is a type of psychological withdrawal. It is a type of giving up, which accompanies the deterioration of the physical state of the person. The patient feels lonely in that psychological withdrawal.

Although the perception of dying is a personal experience, close relatives and friends become aware of the change in the patient's

condition. Both the patient and the family and friends worry about the future, concerning the outcome of the illness. The normal relationships change. The patient is often afraid to discuss his state of illness, and the family is afraid of hurting the patient's feelings, and therefore avoid discussing dying with the patient.

The strained relationship between the patient and the family is further aggravated or worsened by restricted or scheduled visiting hours. In this way, the patient feels isolated and the family becomes increasingly anxious. At times, the patient feels abandoned in hospital and would like to go and die at home. The condition of such a patient might be such that he requires hospitalisation, and therefore cannot be nursed at home. Some patients are hospitalised far away from home, so that the family may at rare intervals visit, or may not afford to come at all (Donovan & Pierce, 1976; Feifel & Branscomb, 1973).

The awareness of impending death brings a message of the inevitability of death, to which the patient reacts. The threat of death brings about emotional and psychological disturbances (Feigenberg, 1980).

The person's reaction to dying is influenced by his personality, <sup>mental illness</sup> personal beliefs, nature of his disease, ethnic background, maturity, life style, age, sex, environment, social situation and the individual's total life experience (Feigenberg, 1980). Knowledge of the diagnosis to some patients causes fear. This fear might be

Public Reaction

18/100

defensive, in which case the patient will not accept the reality of his death. On the other hand, some patients will panic and become depressed once they know their diagnosis (Carfield, 1978; Lord, 1974).

Impending death might mean loss of many things a person values, such as mobility or the savings of a life time. Some people value self-reliance and find it difficult to accept dependence on others for financial, emotional and physical support. The nurses might have a problem with such a patient refusing, for instance, feeding, bathing and being assisted out of bed. Such reactions go along with feelings of loss of self-esteem, dignity, self-worth, and productive roles (Gottschalk, 1982; Roberts, 1976; Charmaz, 1980).

The caregivers will in their care of a dying patient see the dying phase as being characterised by a continuous alteration between the different forms of behaviour and reactions. It becomes important that the caregivers detect the patient's negative and positive reactions so as to give the necessary support.

The impending death of the patient that the nurse cares for, and coming to know as an individual, evokes the sadness of impending loss. The nurse may feel sad about the patient being in severe pain. The nurse has, however, to face the fact that she may not always control all the patient's physical symptoms and emotional problems (Donovan & Pierce, 1976).

✓ The care given to the patient might be physically and emotionally demanding, for example, the patient being too heavy to turn, or very restless (Bohnet, 1982). The nurse may suffer psychological stress if she perceives her inadequacy or unpreparedness to cope with physical or emotional problems of the patient. The nurse might be a perfectionist, idealist, or ever-dedicated so that impending death might lead to her disappointment (Worden, 1982). In the care of the dying the nurse needs to detach her emotions, and this distancing may cause nurses' stress as it robs nursing of its humane quality (Donovan, 1976).

### 2.3.1 Psychological Theories

Psychology and psychiatry have formulated various theories surrounding the impact of impending and actual death on the psychological structure and functions during the dying process.

#### 2.3.1.1 Crisis Theory ✓

Dying and death is regarded by Pattison (1977) as a crisis. The core of the crisis concept is that the current crisis reminds the individual about the final, and unavoidable threat of death.

*attitude.*  
The emotions experienced by the dying are dependent on culture, social order, belief, or experience. These feelings are met each time we encounter a dying person. A dying person feels that he does not have

the resources to cope with his crisis. This means that the dying crisis is an event which exhausts the individual's psychological coping mechanisms, and leaves him tense and in conflict with his former life. This, in turn, generates anxiety which prevents him from handling the crisis situation (Pattison, 1977).

Comments and criticism have been levelled against Pattison's crisis theory. In general the crisis theory states that when the crisis is over, life continues as though somewhat unhibited. In the case of death there is nothing after this and it is therefore difficult to see it as just another crisis that has to be lived through. Secondly, Kastenbaum (1981) admits that the dying process is a crisis for many people, but not for all.

#### 2.3.1.2 Kubler-Ross Theory

Kubler-Ross is an authority in the subject of death and dying, and has done classic research on the topic. Her work has helped health professionals to view death realistically from the point of view of the dying. Her research has revealed that the feelings of patients can be categorised in a series of four stages which most people experience in terminal illness.

##### Fear:

The fear of death that the patient develops is accompanied by shock and denial of the fact that one is approaching death. In the denial

stage the individual may go around "window shopping" doctors for a possible alternate or more positive diagnosis.

Fear may be aggravated if the dying individual is far away from his home or family; for instance, if he is transferred from a local to a city hospital. The family on the other hand, may in their fear of death have feelings of guilt, tension and emotional pain. The nurses caring for the patient, being aware of the patient's condition feel insecure and afraid.

#### Anger:

When doubts about the diagnosis fade, fear and denial are replaced by feelings of rage, envy and resentment. In this disturbed state, the patient resents all nursing and medical efforts and care given him. He resents those who are not ill as well as those who are. Nursing intervention is difficult because the patient is negative, hostile and demanding.

#### Bargaining:

This stage is an attempt made by the patient to postpone the death for the fulfillment of some event. The dying patient sets and imposes a deadline for himself to be able to fulfill that particular event or promise, for instance, attend the wedding of a son, or to experience Christmas. With Christians, such bargains may be made with God, often as a reward for dedication to Him and serving Him, in exchange for some additional time to live.

These bargains are often expressed by the patient to the nurse who cares for him. The nurse should support the dying patient and attend to his wishes. Support can mean assisting the patient to make arrangements for the event/promise to be fulfilled.

#### Depression:

This state is characterised by a sense of great loss. The patient is mourning for all he is losing, for instance his job, status, friends, family, part of the body and life itself. The caregivers should allow the patient to express his sorrow. Some patients remain silent and depressed. It is important that the nurse be able to identify depression and give the necessary support. The family needs to be guided by nurses to enhance the patient's emotional preparation for the approaching death.

#### Acceptance:

At this stage the patient contemplates his coming end with a certain degree of quiet expectation. He has no feelings. He is less interested in what he has valued before. He accepts his final stage of life.

At this time the family needs more help and understanding than the dying patient. Medical and nursing intervention to prolong life are often contrary to the patient's wishes, but this is difficult for the family to accept. If this stage is identified the patient should be

assisted to a dignified death (Ross, 1970, 1975, 1982; Pattison, 1977).

↳ ⇒ Criticism on Kubler-Ross' theory has surfaced over the last few years. Researchers feel that she equates each stage with a particular form of defence against an awareness of approaching death. This division puts the reaction of a person in locked up blocks (Glaser & Strauss, 1965).

Feigenberg (1980) feels that dying is characterised by an unceasing alteration between the different forms of behaviour and reactions. Such behaviour as anxiety, depression, revolt or resignation, form a complex mesh and not a simple linear process.

A family who had read the books written by Kubler-Ross, felt misguided by this theory of stages. They felt that the process of grief included some qualities of anger. The theory made this husband and wife (Rosemary and Victor) understand and know that their feelings were not unique, but it did not assist them to handle their anger (Feigenberg, 1980).

They also noted that the doctor who cared for their loved one was only concerned about the physical aspects of the disease, but had no time for a relaxed conversation that would allow them to bring their feelings into the open. In that, they felt that books on death and dying could be misleading and raise unrealistic expectations in families and patients.

At the end of it all, they said, no two human beings respond in exactly the same way. Kubler-Ross had not made it clear enough that the various stages identified in her book need not follow in the strict order in which she described them, and that the various aspects of dying may be present in any of the stages. Each patient is an individual who makes his own or her own pattern of dying. They would have been spared worry if they had known this at the start (Zorza & Zorza, 1981).

## 2. .2 Sociological Theories ✓

Death is involved in the social structures which man has built, and it has a profound effect and impact on those structures, particularly the family unit (Vernon, 1970). An individual is always thought of as a member of a family, just as death and life are inseparable companions. Death and life are frequently in dispute, but never very far apart, because each depends upon the other (Feifel, 1980).

The key area of sociological study of death is interaction. The problem lies in the fact that, although it is a matter of universal concern, as it permeates the whole society, death has always been a taboo subject. People's desire to know more and talk more about death is a recent phenomenon (Vernon, 1970).

Society has to relearn that death is an essential part of life (Pincus, 1976). Kalish (1977) in his study found that Karelian men

were more willing to befriend or interact with the dying, than women. Women kept a social distance in avoiding the dying.

Dying is a social process, one in which specific or identifiable steps occur. Each society develops its own way of dealing with death and dying. Many individuals are involved in the rituals. It is a social passage, in that it is affected by the actions and choices of the other people who comprise the patient's social world.

✓ Whilst dying involves interaction in one's social world, it is a lonely passage in that no one can "live through" the experience of terminal illness for another (Cassel, 1974; Benoliel, 1976).

Sociologists speak of social death when there is an absence of those behaviours that we would expect to be directed towards a living person, and the presence of those behaviours we would expect when dealing with a deceased person (Pearson, 1969). This situation of social death means the individual is as good as dead. Dying people and the very old sometimes verbalize this condition as a reality : "I am as good as dead".

### *mental illness*

Death and dying has various effects on the family unit. The dying process produces an immense range of emotional reactions, from guilt and anger, to financial worries, to fear and anxiety. Long experience illness preceeding death of a bread-winner as an economic loss. There

can be a need for relocation or even sale of personal possession (Margolis, 1981). When the death actually occurs, the loss of the family member is the most upsetting and feared event. The family structure changes in sex role, social interaction, power relationships, forms of discipline, geographical stability and permanence (Feifel, 1977).

*olden days*

In olden days dying occurred in the privacy of the family circle. There was companionship of the family at the time of death. The elderly of the family and neighbourhood sat at the bedside of the dying, giving care and psychological support to the dying (Kalish, 1977). This was similar for the Zulu, where the elderly women remained at the bedside of the dying person. It still happens in the rural Zulu communities.

Social change and development has brought about fragmentation of the family, and the dismantling of rooted neighbourhood and kinship groups with homogeneous values. Death, therefore, has been removed from the family and common human experience, to health professionals in institutions, to undertakers and even given publicity in the news media, like television. People no longer meet death in the privacy and security of their families. Death is no longer accepted. It is seen as a destroyer for communities that emphasise achievement, the future, the right to live, and the happy future (Feifel, 1977).

Society has endowed social occupants and institutions with a mandate which denotes their purpose, functions and values. So, we see the roles of the health professionals in caring for the sick and dying, being ascribed to social expectations (Kubler-Ross, 1975). There has been an expanding recognition of psychotherapeutic value of open communication with the dying in clinical management. The health professionals believe in honest and sensitive talk from the staff about the patients' condition. They believe that dying patients do not expect miracles, but confirmation of worth through care and concern (Feifel, 1977; Kubler-Ross, 1975).

The training courses for caregivers, particularly nursing and medicine, are the means of ensuring that they meet social expectations for caring for sick and dying people. Studies into the care of terminally ill have, however, shown that the training that nurses and doctors receive primarily prepares them for the technical aspects of dealing with the terminally ill. The inclusion of psychology into their curricula has not improved their preparation. The nurse teachers often merely teach the students how to give technical care. (They do not emphasise adequately how they should talk to the dying person. They often avoid the topic of death and call the psychiatrist to sort of give an "expert testimony" about the dying. The result is that even the trained nurse avoids the dying patient, or denies this aspect of reality to the extent of not even being aware that she is dealing with a dying patient (Strauss, 1987; Quint, 1976; Glaser & Strauss, 1982; Whitman, 1975).

Nursing has since the Florence Nightingale age been regarded as an occupation that offers personalised services and physical ministrations to the sick and dying people. Direct-physical-care was considered to play the major part in effecting recovery, until the advent of antibiotics and complicated medical therapies and technology, which made nursing more technical (Benoliel, 1975(a)).

Specialisation has led to fragmentation and depersonalisation of experience of human death (Kastenbaum & Aisenberg, 1972). Dying patients and their families find themselves in a complex medical system that attaches high priority to life-saving procedures and technical activities and is poorly organised to offer personalised care (Feifel, 1977). To me it seems that specialisation in the care of the terminally ill as seen in the various Hospice Movements, has been a response to the felt need of once more humanising nursing and medical care.

✓ There has been a growth of professional interest in the problem of the dying, which has resulted in two major professional attitudes (Pattison, 1977). The first is the exaggerated detachment, which means that an emotional distance is maintained. ✓ Dying is made a thing and an object of scientific enquiry, and thereby the threat is removed. It has become an impersonal, objective, external problem. People are now, according to the professionals, supposed to die in a certain way, so called the "right way". The professionals look for a

logical and rigid patterns for progression of dying, so that they can rigorously follow the scientific course of action. Dying is made acceptable through professional objectification.

Secondly, the professionals may develop exaggerated compassion. In this professional distortion, as Pattison calls it, there is fusion with the dying. The professionals identify with the dying person, and in their work seek to undo past guilts, relieve past shame, restore person's self-esteem, and anticipate their own death anxieties. They live, die and are reborn with each dying person (Pattison, 1977). Professionals with this attitude are sympathetic with the patient. To them dying is made acceptable through subjectification.

The nurses are the main caregivers to dying patients. This is so because, all the other health professionals, like doctors, physiotherapists, radiographers and others, only see the patient for a short period and depart, whilst nurses remain for the day or night shifts. The nurses, therefore, play an important intermediary role between other professionals and thus create a healthy therapeutic relationship. This relationship is open and caring, permitting, sharing, supportive to the patient and his family (Brown, 1982; Chapman, 1980; Tousley, 1982; Bohnet, 1982).

#### 2.3.2.1 Awareness Theory

Glaser and Strauss (1965) in their study of death and dying, focussed

on their care and came up with the awareness theory. It indicates that the caring team intervening become aware that the patient is dying, but withhold this information from him. The patient progressively weakening, sees his treatment being changed. If he asks, he is given another reason. The patient may build false hopes of recovery, and plan for the future. The family members may, for various reasons, also withhold the information. One of these reasons for instance, may be not being capable of dealing with such a situation, or may feel they should spare him the burden of knowing.

After this phase of closed awareness the patient starts to be suspicious that the caring team does not know about his progress. He starts asking about his prognosis from the junior staff, up to and including the doctor. The patient at this stage makes scrutiny of all responses, verbal and non-verbal clues of staff and family, to get the information about his condition. The patient might not be expecting to be told the truth. The caregivers and the family might fear to tell the patient in case he loses hope; and remaining sad or morbid for the rest of his time. This might make nursing intervention very difficult with an unco-operative patient, and then becomes haunted with a feeling of failure.

Then comes a time when the patient, family and care-givers all know the patient is dying but pretend they do not know. There is vagueness and confession in the avoidance of the topic by the two parties in an effort to protect each others feelings.

The final context of this theory is open awareness. In this situation the caring team have told the patient and the family of the imminence of death. The communication is open, encouraged and elicited. In this way the dying process is less difficult for the dying patient and with anticipated grief, the mourning becomes less distressful.

Quint (1967) made a similar observation that the nurses were reluctant to deal openly with dying patients. This was ascribed to their lack of theoretical training and the paucity of field experience with adequate role models.

A survey of thanatology literature by Feigenberg (1980) noted that the findings of this sociological awareness theory is of great value for persons engaged in the care of the dying. The structure of problems around central themes produces a meaningful picture, and an answer to the many details that had been noted or wondered about in connection with the care of the dying. These details are in this theory, integrated into an intelligible general pattern.

The awareness theory contains descriptions of situations, processes, conflicts, that constantly occur in work with the dying, which greatly assists the multi-disciplinary caring team.

## 2.4 SUMMARY

Approaches to death and dying have indicated that it is a phase of life, a process of degeneration of biological functioning of the body, a process that comes from within a person, and a process that some see as leading to an afterlife. Reactions to impending death vary and psychological studies have revealed that it may be a crisis, and that an individual passes through the stages of fear, anger, bargaining, depression and acceptance. On the other hand the sociological theories of awareness also gives a meaningful picture of death and dying. These approaches and theories to death and dying form a theoretical framework from which patients' needs can be assessed and their care improved, but further research in this field is a necessity.

## THE ZULU CULTURAL VIEW OF DEATH AND DYING

## 3.1 INTRODUCTION

In South Africa although we live in a single society, we are continuously coming into contact with different and often, it appears conflicting, cultural and belief systems. The hospital is a microcosm of the wider society and as caregivers we come into daily or even hourly contact with different cultural views and religious beliefs. These influence our ways of dealing with our patients, their families, and with each other.

As caregivers we come to our training with a set of beliefs to which we add those of our medical and nursing training. We, then, develop a learned professional way of dealing with the sick, their families, and each other, but it must be noted that the nurse herself has at times got to perform what are referred to by Zulu speaking people as "amasiko", that is customs. These "amasiko" do not usually interfere with our nursing careers, but are an essential part of our lives and existence. As we will see later, they are related to Zulu conceptions of health, illness and death in which the ancestors or "amadlozi" play a vital role.

On ward inspection in April 1988, I came across a student nurse wearing an "isiphandla", that is a bracelet of goat skin around her wrist. She told me she had undergone the "ukwemula" ceremony. This involves a slaughtering of a goat to mark a girl's entry into puberty or marriageable state. In her case it marked her twenty-first birthday. I congratulated her as was appropriate, but I drew her attention to the danger of cross-infection.

This was a problem that I had met in my own life. Some years ago, the elders in my family felt that the problem of giddiness which I had experienced for some years after marriage, occurred because my father did not perform the same "ukwemula" for me. The doctors had diagnosed my ailment as hypotension. I believe and know that the doctors are correct, but I felt it was also important to "ukwemula". This "ukwemula" was performed for me in July, 1986 - twenty years after my marriage. I had to wear an "isiphandla". Seeing I was only off duty for two days and could not wear the "isiphandla" on duty, I sought advice from an old man. He advised that I burn the "isiphandla" with incense in my house. I suggested this solution to the student nurse and she accepted it whole-heartedly.

Other nurses also attend their families' "amasiko". They ask for certain weekends off, to join their families in the performance of "amasiko". A nurse for instance who has lost a husband, her child, or her mother-in-law (if she is the first bride), is released immediately from duty, as she becomes the chief mourner. As a chief mourner, she has to take her place, to sit at the "umsamo" (the sacred place at the rear end of the main room), on the mat and cover her head. She cannot return immediately after the funeral, as people coming to "ukulila" (to mourn), have to find her at home. She returns to work at least two weeks after the burial. This leave of absence we accept in the hospital as 'compassionate leave' but few white doctors realize that it is important in a religious as well as emotional way for a Zulu nurse.

There are times when patients say "ngifuna ukuya ekhaya ukuyokwenza umsebenzi", that is, "I want to go home to perform a custom." Often the "isiko umsebenzi's" details are not stated, unless there is already a warm personal doctor/patient or nurse/patient relationship. The nurse as interpreter at times fears or feels ashamed of her and her patient's culture and fails to interpret exactly what the patient says. This often ends up with the doctor assuming that the patient is reacting negatively to hospital treatment. Of course, there are times when the doctor is told exactly what the patient has said, but even so refuses to let the patient go. The doctor's refusal is understandable, because if the patient's condition is critical, he cannot ethically or legally allow a pass-out. It requires that the patient signs refusal of hospital treatment (RHT) form, and leaves at his/her own risk. However, if there were understanding and consensus between the caregivers and the family, the latter would sign the patient out, and he/she would be brought back as soon as the "isiko" has been performed. The case of Mr C..... (here below) is an instance of the conflict between Zulu and western beliefs systems and how I solved the problem.

In 1985 a Mr C...., who is a practising Christian and well educated, the husband of one of our nursing sisters, met with a car accident. He was admitted with a badly severed right leg which had to be amputated below the knee. The researcher had known this gentleman long before this incident. On ward inspection he was seen and he expressed his gratefulness to God who saved his life. He even said he thought he had not been good before the eyes of God, and that had been the way God was reminding him of His great power.

One day, about the third week of his admission, a message was received that he wanted to see the researcher. He then confided in the researcher that, on the day he met an accident he was picked up from the accident scene and taken directly to the hospital. On that day his "amadlozi"/ancestors had seen him leave for work in the morning, but they never saw him return home. To them, he was like a person who had absconded from home, and that annoys/angers the ancestors. Seeing the ancestors are foolish/"izithutha", they cannot detect that he was in hospital.

The worry about this situation had been with him since admission. He told the researcher that his stump would never heal, because the ancestors were angry. He showed me his stump that was not showing any healing progress. He told me how good his surgeon was, and said he had sent him twice to the operating theatre, but with no significant improvement in the healing process. The surgeon had informed him he was to go to the operating theatre for the third time, the following week. He felt it was high time he went home on a pass-out, over the weekend, to inform his ancestors about his ordeal. He felt it was not safe for him to undergo general anaesthesia when his ancestors were so angry with him. He might not regain consciousness from anaesthetic. This made him very anxious and he felt very insecure.

At home he was to slaughter a goat for the ancestors, inform them about the accident he met, and then report his departure to hospital, so that they could accompany him to the hospital. The performance of this custom would pacify and appease the ancestors so that they would accompany him to the hospital to protect him, which would assist the doctor by making the operating successful.

The researcher asked the patient what had happened to his faith in God, whom he had said saved him. He said it does not mean that one has to discard his culture and customs when one is a Christian and educated. He said, the white missionaries performed their own customs like placing flowers on the graves of their deceased loved ones. By that it does not mean they worship the dead. When a Zulu slaughters to remember the dead family member, he is said to be worshipping the dead. He said, why do Whites have to break a champagne bottle for launching a new boat or ship, for winning a car race. He said it is their custom. He said the Zulu regard ancestors as a host of angels - guardian angels, but there is a Creator - "Mvelinqangi", that means, "One who emerged first."

His pass-out request, he felt should be presented to the surgeon by a person such as the researcher who was respected by the surgeon, because she is a nurse administrator, rather than merely the ward sister. The surgeon, when approached, was very reluctant to give him a pass-out. He, ultimately agreed however, when the researcher pointed out that the patient might refuse to sign consent for operation; and that he also needed psychological care. On his return he was happy, relaxed, hoping for a successful operation and healing up of his stump. The nurses and the surgeon informed the researcher about his positive attitude. He assisted in lifting up his stump when examined by the surgeon and when being dressed by the nurses. He co-operated with the physiotherapist, whom I was made to understand, had found him very unco-operative with exercises previously.

Some months later, when he had fitted his artificial leg for the first

time, he came to the administration block to look for the researcher. He was jubilant and shouting, "uphi umama?" (where is my mother?). On checking who was making this noise, there he was, "Mama ngibuke ngihamba! Isidalwa esisha. Ngiyabonga mama wami" (Mother see me walking! A newborn creature. Thank you my mother). He shook my hand in gratitude several times, expressing that his present state of recovery had been achieved because he had been allowed a pass-out to perform the slaughtering custom, for informing his "amadlozi" that he was in hospital. He emphasised that if the researcher had not explained his fears about the angry ancestors to the doctor, he might still be lying in the ward with an unhealing stump. The researcher was later invited and attended his thanksgiving party to "ukubonga abaphansi" - thanking the ancestors, and God. Even when his daughter was celebrating her "ukwemula", in July 1987, the researcher was invited and attended.

✓ In rendering nursing care to the Zulu patients who are ill and dying, one cannot but perceive how they explain their illness and what caused it. It is important to listen and discuss these beliefs with the patient as they contribute towards the patient's motivation to participate in his/her medical and nursing care plans. The beliefs are often referred to by both the people themselves and by the doctors and nurses as "their culture". It is, perhaps, necessary at this point to explain my understanding of terms such as culture, belief systems, family and society because they will be used constantly in this thesis.

### 3.2 CULTURE

There are almost as many definitions of culture as there are writings on this topic. The ones which make sense to me are as follows, "Culture is a shared system of knowledge and beliefs by which people order their perception and experiences and make decisions and in terms of which they act. It is a shared system of ideas, a kind of conceptual code that people use to interpret themselves and the world and to formulate behaviour." (Frank, 1978 : 19). Caplow, (1971 : 19) defines culture in a more deferential manner as the "grand total of all objects, ideas, knowledge, ways of doing things, habits, values and attitudes which each generation in a society passes on to the next."

Culture is never static. It is added to, may even be built anew by each successive generation. The adaptive mechanism of culture enables the sharing of meaning in people's daily lives. So, the learned, accumulated experiences are socially transmitted patterns for behaviours characteristic of a particular social group. (Keesing & Keesing, 1971). To put it and in a way, culture refers to "ideational things", conceptual codes, in people's minds. A social thing refers "to behaviour, behaviour patterns, regularities in interaction between persons as members of a society." (Frank, 1978 : 19).

The word culture is often used interchangeable with society. When I speak of society as a social group, I am referring to a collectivity of individuals who recurrently interact in a set of institutionalized and connected identity relationships. In other words, we find people acting in various capacities towards one another and it is to these

that we refer as social relationships (Frank, 1978). In a hospital the caregivers are a social or professional group that acts in identified or expected and institutionalized relationships with each other, the patients and with the families and relatives that come with or visit the sick.

### 3.3 BELIEFS AND BELIEF SYSTEMS

Culture amounts to a set of complexly interwoven (and often as we will see apparently contradictory) beliefs about the world around us - how it is, and ways of dealing with life and the things that happen. One of the recurrent crises of life is illness and culture and belief systems explain its causes, death and what brings both illness and death about. So, culture or what we call culture, can be best thought of as ideas about how things are, and how things should be done. So, with this definition of culture it is possible to argue that people have a lot of different ideas about the cause of illness, and how one can best get better or should behave. Often we are not sure which plan is right and we are swayed by what other people say. For example, Zulu speaking people may go to hospital because they think that the best treatment is available there. When, however, one is there in pain and dying, one may think in terror that it must be witchcraft causing the illness and then one needs to go to the "inyanga" (witchdoctor) or "isangoma" (diviner). One may think of going to perform "isiko", for instance to wash off "umnyama" (pollution). After the performance of "isiko", one returns to the hospital, accepting all the treatment and the care they have to offer.

In dealing with patients we are aware, we are dealing with individuals

who think and in whose minds there may be different explanations and rules for alternative ways of doing things and coping with crises of illness and impending death. Often our patients tell us they have been to the "umthandazeli" (prayer woman) or "inyanga" or "isangoma" before coming to hospital. So, this means, a person gets comfort from christian prayers - it does not matter which church, or performing "isiko", and for some it is just the doctor's treatment.

It is important to emphasise that the differences in culture and cultural beliefs does not mean that some cultures are better than others or that some are more primitive than others. All provide satisfactory explanations of illness and people from different cultures often borrow each others belief systems. In this chapter Zulu cultural beliefs relating to death and dying are highlighted as is the constant mixing of a "traditional" western, and "traditional" Zulu view. In addition, there are differences in western ideas on death - a christian and a secular/medical one. Most of the nurses, including the researcher, have been exposed to aspects of various beliefs, that is, strict christian (from missionaries), "traditional" Zulu, from which our home backgrounds and patients, and "modern" Zulu peers and colleagues. Also, as nurses, we are open to a western medical view, which is not necessarily fully shared by all western people and certainly not by many strict christians.

In summary culture is learned human behaviours - a set of ideas about how things are and how to behave. So, culture is a learned blue print for action and any person can learn about new ways and either follow or reject them, or combine his/her existing ideas with the new ones.

My autobiography which makes up the next chapter illustrates this point well.

#### 3.4 THE FAMILY CONTEXT

Although the words culture and society are often used interchangeably, it is better to distinguish them. In this thesis society is defined as a group or population of people separated physically (and to some extent by its culture) from other similar units. The most important aspect of cultural difference is the language. Just as culture is not static, neither is society. "It has been suggested that the modern world is not divisible into distinct societies, for the groups of the world have become so interdependent and engage in so much interaction that it is almost impossible to designate the boundaries of any particular society." (Frank, 1978 : 19).

One of the most important components of society is the family. The family structure and function may vary in different societies and cultures and at different times, but it remains the basic group in all human organisation. This is because it provides its members with their first experiences of other people, as well as their earliest definition of themselves, and the world in which they live. The family is the integral part of society, and no change can take place in the one without affecting the other. (Harris, 1969).

It is particularly important, in this study to take note of the nature of the family in Zulu rural communities as the hospital in which research was done serves a large rural area. Although some people do

live in nuclear families, most rural people at some time in their lives live in a form of extended family. It is usual for a man to bring his bride to live in his father's home and old people are usually living with their married sons and their children. In fact the "umndeni" (household) may be made up of a number of married couples and their children and grand-children. Such a domestic unit is under the head of a senior male - the "umnumzane", who is the genealogically most senior male in the unit. Under the headship of "umnumzane" the "umndeni" is a cluster or segment of two or three generations "which acts as a corporate group in the control and management of common resources, such as land, and in the settlement of internal disputes." (Preston-Whyte, 1982 : 8).

The "umnumzane's" position is ritual and the ancestors are approached through him. He presides over any "isiko" performed by the "umndeni". He is the decision-maker and guardian of the illegitimate children of his sisters and daughters. If the senior male dies, his brother becomes the "umnumzane". Children in the "umndeni" refer to the senior male as "ubaba omdala: (elder father) and his brother as "ubaba omncane" (younger father). When (as Zulus) we refer to uncle - "umalume", it is the mother's brother. We understand though as Zulu speaking people that people of other cultures refer to both paternal and maternal uncles in the same manner. It is only when there is neither "ubaba omdala" or "ubaba omncane" that the first son becomes "umnumzane".

### 3.5 ZULU BELIEF SYSTEM REGARDING ILLNESS, DEATH AND DYING

#### 3.5.1 The Totality of Human Experience:

Zulu speaking people believe that a person exists as a totality - as a whole physical and spiritual being. The body forms the physical aspect complemented by the spirit or soul, or the "idlozi". When a person is sick it is both his body and spirit which are affected. (Krige, 1965; Berglund, 1976; Raum, 1973). To be successful treatment for both his physical and spiritual aspects is necessary. So that, when the medical doctor has given physical treatment the patient if he or she has not directly consulted a traditional healer, will on discharge, go to either the "inyanga" or "isangoma" or "umthandazeli" to "ukuzwa" (to hear) what has caused the illness, and how it should be dealt with. This usually involves performing the necessary "isiko" - a ceremony, aimed at speeding up recovery, or to ask and thank "amadlozi" for their protection.

In western medical and nursing science point of view, physical and spiritual death are two entities - as explained in the previous chapter. Many doctors and nurses do not feel that it is their responsibility to prepare the patient spiritually for death. They call or allow the clergy to do this in their multi-disciplinary health care approach to patient care. They realise by and large the importance of this spiritual care but, in fact, only make use of christian concepts, taking no cognizance of Zulu views. It might be necessary for Zulu speaking patients to call an elderly family member to perform death rituals, such as informing the "amadlozi" that they are being joined by the dying person.

### 3.5.2 How The Ancestors Are Conceived:

The departed spirit or soul, the "isithunzi", is through the slaughtering ritual, turned into an "idlozi" that goes under the earth, to dwell with the other "amadlozi" of his lineage. The "amadlozi" or "abaphansi" dwell underground. The realm of the deceased is the shadowy existence underneath the earth.

The "abaphansi" are also referred to as "izithutha"/the foolish. They are referred so in the sense that they cannot physically help themselves. They cannot supply themselves with food and have to rely on survivors. They are also foolish in the sense that there is someone greater than themselves, who is powerful to do anything at any time, that is, the Creator, the Lord of the Sky, who created the universe out of nothing in His Hands (Berglund, 1976, Ngubane, 1977). The Creator in Zulu is called "uMvelinqangi", that is, "One who emerged first."

The abaphansi/ancestors/spirits of the dead, are also referred to as "amathongo". The noun "ithongo" is derived from the noun "ubuthongo"/sleep. The "abaphansi" or ancestors appear to the living in dreams, and these dreams are a reality in Zulu culture. The ancestors are faithful in caring for their survivors, for example they visit them in dreams, which is a reality. They can bring special messages as to what has to be done for them, can bring warning messages to alert survivors about impending danger, reprimand. The survivors have to act promptly to the demands or needs of ancestors, unless they are angered (Krige, 1965; Raum, 1973).

As a Zulu, I have grown up knowing that when one never dreams seeing any of his ancestors, he feels deserted and anxious. Also that at least once a year slaughtering must be done and Zulu beer made, to appease them. Since my father-in-law died in 1978, my husband buys a goat or sheep to slaughter at Christmas at his home. I personally make Zulu beer. In 1986 we did not slaughter and when he became ill, we thought it was because we did not slaughter. We had to do the "isiko" - slaughter and he was better.

The ancestors remain underground. As they are in spirit form they can in spirit form accompany and protect an individual, like a guardian angel. They protect their survivors, of their lineage. It is therefore important that a person who has died is buried at his home, next to the graves of his forefathers. (Krige, 1965). Even nowadays, the burial of the family members in the same graveyard is strived at and it gives satisfaction to whole lineage.

As a nurse I have observed that when a patient has died in hospital, the family comes to take away his lingering spirit. Often when they come to collect the body from the mortuary, they also come to the ward where he died. They come with an elderly man or woman who carries a small twig of ziphuf-mucronaea (umlahlankosi or umphafa) which carries the spirit. This is the "buyisa" custom, that is "to return him home."

The family often wants to be shown the bed on which the person died. This is discouraged as beds are moved around in the Ward, and it would upset the patient sleeping on that bed. They, then resort to putting

the twig on the floor at the ward entrance.

The custom is then performed. This elderly person calls the deceased by name. They would for instance say, "Themba, Themba, I am your eldest brother Sibusisio, born of your father Jabulani, born of your grandfather Thulani, of the house of Dlamini. I have come to take you home. Themba let us go home, to your family." He will then pick up the twig, and from that moment never utter a word, or turn to look back until they reach home. But if they are taking the corpse home, he will put the twig on the coffin. When they put the coffin into the vehicle, he shall pick up the twig and talk to it (as it is carrying the spirit) and say, in this example, "Themba we are getting into the vehicle." Once the coffin is placed into the vehicle he will put the twig on top of it again. When they reach home he will pick up the twig and say, "Themba let us get off from this vehicle, we have reached home. You have reached your people of your lineage." The vehicle parks at the gate or in the yard next to the gate. When the coffin has been placed in the house, the twig is placed in granny's hut or in the kitchen or the room where the Zulu beer is placed. This is to show him the food prepared for him and the ancestors. As he puts the twig down, he will say, "Themba, we are at home, now join your ancestors. We hope you shall be a kind, protecting ancestor."

The elderly person will then walk right round the yard and speak to the spirit, saying his life time praises if an adult, and saying the clan praises, informing him they are about to slaughter a beast in his honour, and to let him join his ancestors. When the beast has been slaughtered the meat is placed where the twig has been placed in the

granny's hut/kitchen. The granny's hut is preferred as she is elderly and closer to being an ancestor. The beast can be slaughtered before the corpse comes home. The meat will be placed in the same hut/room with the Zulu beer.

This "buyisa" return home custom can also be performed long after the death of the person, usually after a year. The researcher has experienced this in her nursing career from the late 50's, and each time she asked the people, who came, the above explanation was given. This custom is carried out by christians and traditional Zulus. At times, the christians perform this "buyisa" custom under the cover of unveiling the tombstone. My father-in-law's tombstone was unveiled in 1985. My great-grandfather Wellem who was buried at the Lutheran Mission called Christianenburg at Clermont in Pinetown in the early 1920's, often appeared to my eighty year old mother in dreams, saying he wants to come home. So, the buyisa custom was performed for him on 11 June 1988. My younger brother who is a principal clerk at the Magistrate's office, went with my eldest brother to bring back his "isithunzi". They took along a ziphuf-mucronaea twig, to take the spirit with. On return, my eldest brother had to sit at the back of the bakkie to ensure he did not speak. When they reached home, at Eshowe, he talked to the twig as if talking to our great-grandfather telling him, they had reached home, and then took the twig and put it in the kitchen where there was meat and Zulu beer at the "umsamo".

The unveiling of a tombstone ceremony is often performed a year or two after the burial. Invitations in the form of cards are sent out to relatives, friends and the community that attended the burial.

A radio announcement is also often made nowadays during the announcements programme during the week days at 05h40. A day before the unveiling ceremony a beast is slaughtered, and Zulu beer is also made. The relatives, the neighbours, as well as members of the family's congregation come to an overnight revival meeting. Hymns, choruses, are sung, prayers and testimonies made by the members right through the night. The next day all these people are transported by a hired bus to the cemetery. After the unveiling ceremony conducted by a pastor, they return home to feast.

### 3.5.3 Dreams and Dreaming:

Patients tell of their history of illness and at times express that they dreamt of the misfortune of illness. It must be understood that dreams are a reality in Zulu speaking people, as it is with other societies. "To dream is to see the truth at night. If a man says something and you dream about it differently at night, then you know that the man is misleading you. It is the dream that shows the truth, because the shades never deceive their children" (Krige, 1965 : 79). The patients tell nurses of their pleasant or unpleasant dreams. The pleasant "iphupho" (dream) motivates the patient to participate in the care plan. The unpleasant "iphupho" requires discussion with the patient and involving the patient's family. The nurses need to improve their attitudes towards patients' dreams, and consider listening to patients as they relate their dreams, just as they take their dreams seriously. As a nurse administrator, one has, now and again, to break bad news to the staff. It is common to hear a nurse say, "Ngivele ngasola ngephupho engivuke nalo, ukuthi kukhona engizoluzwa" (I suspected from the dream I "woke up with", that there

are some bad news I am going to hear). Zulu speaking people know, for instance, that to dream about a feast of meat means a death in the "umndeni".

The doctor is not told about the patients' dreams, neither are they recorded as what the patient verbalised. One can only assume that nurses being Zulu speaking and having general knowledge that westerners and western science (which includes medical and nursing sciences) tend to play down the influence of dreams on people. This practice should be changed and I shall return to this point in the conclusion of this thesis.

#### 3.5.4 Other Major Causes of Illness - Sorcery, Pollution: ✓

"Zulu find themselves involved in and affected by the realm of the shades on the one hand and that of "abathakathi" on the other. While, in the lives of men and women, the shades in many respects are the explanation to sickness, ....., "abathakathi" are the answer to all calamities which cannot be traced to shades" (Berglund, 1976 : 270). "Abathakathi" are sorcerers. It is always perceived that illness is caused by an evil person, through the activities of sorcery. The shades as such do not directly cause illness, but when angered withdraw their protection and thus the individual becomes vulnerable to sorcery.

"Rural settings offer a profound belief in both witchcraft and sorcery, although the cases of either overlapping or only sorcery dominate the minds of people. In the urbanised area emphasis is put far more on sorcery, only people being convinced that witches practice

in cities" (Berglund, 1976 : 270). In my personal experience in rural and urban communities both sorcery and witches activities dominate the people's minds. The witchdoctors make a lot of money in the performance of "ukuqinisa" (strengthening) people's homes. The witchdoctor buries "muthi" (herbs) which is protective to family members at the gate entrance and at the four corners of the plot. Last year in this township in which I stay, a middle-aged woman was caught at night digging a hole to bury "muthi" in the neighbourhood, she was half-naked. She was made to pay the beast to cleanse that family of the pollution by that "muthi" and by her being half-naked among the "umndeni" with its ancestors.

"Umnyama" (pollution) is conceptualised as a mystic force which diminishes resistance to disease, and creates conditions of poor luck, misfortune (amashwa)....." (Ngubane, 1977 : 78). In the state of "umnyama" the "amadlozi" cannot provide their protection. The "umnyama" has to be warded off through the slaughtering custom to "geza umnyama" (Ngubane, 1977). This is one of the reasons that our patients want a pass-out for, when they have a slow recovery progress which they consider as "amashwa or umnyama" and therefore go home to slaughter for "amadlozi" to appease them for their protection.

The illness itself is thought of as being "umnyama", as already explained that pollution diminishes resistance to disease, and creates "amashwa". So, "ukucela izinhlanhla kwabaphansi" (pleading for good luck from ancestors) cannot be overlooked. (Ngubane, 1977). The "umnyama" is dangerous because patients say it even clouds investigations by the doctor. When a patient has, for instance, to go

for a repeat X-ray because the first one was not clear, he/she immediately becomes anxious that there is "umnyama", and that all his treatment might be unsuccessful. Even the misfiling of the out-patients' record or the old in-patient file does cause anxiety of "umnyama". So the position of the ancestors has to be strengthened with Zulu speaking people, in illness. If the patient's treatment or operation is successful, the remark "abaphanzi babenami nodokotela wami" (my ancestors were with me and my doctor).

#### • 3.5.5 Concepts of Death:

For the Zulu death is a mystery associated with the other world from which people come (at birth into this world) and to which they return in spirit form. The cessation of life in this world is believed to mean the continuity of life in the other world. Life is explained as starting in this world, although it is said to be initiated from the other world (Ngubane, 1977). In Zulu philosophy, when life begins a human is seen in totality - body and spirit or soul, an "idlozi" (Berglund, 1976).

The Zulu have two cultural concepts of death, a timely death and an untimely one.

##### (i) Timely Death:

This is the death of an elderly person, who is passing on to the next world of "abaphansi". It is expressed as "ugodukile" - gone home, or "udlulile" - passed on, or "uhambile" - gone. The home referred to is

that of "abaphansi" of his lineage underground (Berglund, 1976). The Zulu speaking people have generally a positive attitude to death of elderly people. This death is accepted as a timely death and there is no wailing. (Berglund, 1976 : 79).

In my nursing experience I have observed that when a young or elderly person is so ill that death is inevitable the family also develops a positive attitude to death. In a sense mourning begins before death when the family accepts death as timely and inevitable. The family will have done all in lines of treatment - tried the "inyanga", "isangoma", "umthandazeli", private doctors and the hospital. When such a death occurs the family would simply say "uphumulile ezinhlungwini" - he/she has been relieved of the pain or suffering (literally "rested from pain"). Such acceptance and positiveness does not seem to exist in Western belief. They would say it was a blessed release, but they do not, by and large, let either the very old or people who are chronically ill die in peace. They do all they can to keep them alive. For Zulu speaking people there is no urgency in rushing a very elderly person who is sick to hospital. It is considered as being unkind to that senior citizen. Actually the very elderly person does in normal conversation point out that they have done their duty, and wish to join their ancestors.

Before the White man's rule, an elderly person who could hardly walk, eat and whose family and society pitied that it was painful for him to live, was assisted to die. The "ukugodusa" (sending the aged further) "isiko" was performed by the eldest son (Berglund, 1976).

The concept of death as "ukugoduka" has been and is still experienced in nursing the Zulu speaking patients - both old and young adults. The critically ill patient will just ask the nurse to inform the doctor that he/she wants to "goduka". At times the patient informs the family at visiting hour that he/she wants to "goduka". At times the patient even states that he/she wants the family to slaughter a beast as he/she wants the fresh liver. The patient would express it as "ngifuna isibindi". It is then understood that the slaughtering is "isiko" to "ukuphekezela" (custom to accompany the spirit to join the ancestors). If the dying person cannot eat the blood of the beast is smeared on his/her lips. So, the Zulu speaking nurse will always perceive "ngifuna ukugoduka", that the patient is actually saying "I want to go home, to my people and "izithunzi" to "goduka"/die in their presence, care and with dignity." At times the patient may want to go home to perform "isiko" which he had neglected earlier in his life out of the feeling of guilt, and then die.

The family always try their best to get transport to take the patient home. If the doctor refuses to discharge the patient, the relatives are always willing to sign for refusal hospital treatment and take the patient home. If the nurse explains (very rare) what "goduka" means, the doctor often signs the patient out and makes an entry in the patients file that the patient is discharged at his/her request to die at home. This creates a positive attitude in the family that doctor respects their beliefs and it strengthens acceptance of western medicine. The doctors sympathetic attitude is communicated to the family and all the people that come to that family to mourn and to attend the burial.

The relatives always feel obliged to respect and fulfil the person's last request in this life - to die at home. In addition, it is economical to transport the person home alive, rather than as a corpse. They often say, and this is also known to the researcher, that a vehicle that has transported a corpse is polluted. It, therefore, requires that its wheels be washed off the "umnyama", by using water to which has been added "umswani" (goat stomach contents). This is where the expense lies as the goat has to be bought and slaughtered by "umnumzane".

(ii) Untimely Death:

The Zulu do recognise untimely death which is known to be due to unnatural causes. It is regarded as an extinction or breaking off of life. In Zulu terms it is referred to as "ukufa" or "ukugqibuka" or "ukubhubha" - all meaning the sudden extinction of life (Berglund, 1976: Ngubane, 1977). The cause of untimely death as noted above are often thought to be witchcraft or sorcery. The cause of untimely death is often sought from the "isangoma" who will say what "isiko" or preventive measures are to be taken to strengthen ancestral protection.

3.5.6 Mourning and Death Rituals:

Mourning procedures are the society's reaction to actual death. For the Zulu mourning begins possibly even before death and is strictest until burial before which no work should be done. There is no working in the fields (or gardens), no rejoicing, no singing. The chief mourners (females) remain seated on mats. The neighbours and visitors

come and sit, weeping loudly for some time. They then say a few words of sympathy to the relatives. (Krige, 1965). This behaviour is still practised both in rural and urban communities.

The researcher can recall the wailing she witnessed in the 1950's, at her neighbourhood at Eshowe. Grandmother Ngema had died. The women came and waited for each other at the gate. When there were about ten of them, granny Sikhakhane who had a high-pitched voice started the wailing. It was wailing up to the doorstep, where they started a hymn. They sang until they were all seated. Granny Sikhakhane in her prayer asked God, to kindly send grandfather Ngema (who had died five years ago) to meet granny Ngema at the death river Jordan, and assist her across to heaven. Later, the researcher understood that there was confusion among the elderly about where exactly Israel is. This also clearly displays the influence of religion in explaining death, and the fear of that time/marginal overlap between death and burial.

The chief mourners are always women in Zulu culture, who have to show great respect and weep openly. In traumatic deaths, such as drowning, car accident - they sit near the site/scene of accident whilst men prepare for the burial, which must be conducted on the same day. The corpses in these cases are never brought home, for fear of "umkhokha"/recurrence pollution. (Ngubane, 1977). These days, however, the body is kept in the mortuary and then straight to the church/or to the graveyard.

The grave is dug by male mourners. The burial is a very solemn ceremony. A young person is buried in the morning, and an adult in

the afternoon. When the body has been lowered into the grave the head of the family, who is always a male, throws the first sod into the grave, followed by close relatives to say good-bye. (Krige, 1965).

Rituals are prescribed behaviours, based or justified or made necessary by attitudes or beliefs of a community. They are a symbolic language that expresses the feelings of the community more than words. They are a form of joint worship. They may have a healing and sustaining power (Humphrey, 1982; Holland, 1985). The ceremonies and rituals are strategies that are intended to mute, mollify, explain and redirect the elemental threat implied by death (Weisman, 1982).

The various societies in the world respect the dead and the performance of particular rituals and ceremonies have a social function. Customs and creeds always preserve a discreet, sanctified and euphemistic distance from death. In order to approach or touch death things, or things that have been touched by death, the society insists upon special rites formulas and even select certain members of society to take our place or argue our case with lethal forces. (Weisman, 1982). Performance of rituals and respect for the dead are symbolic and show that the status of the individual does not cease in death. (Shanley, 1982; Tonybee, 1968). The performance of rituals cover two areas, that is, for the dead person and for the protection of the family and nearby community. In other words, rituals or rites of passage or suitable responses, which guarantee both the serenity of survivors and the souls of the dead.

The bereaved family, from the time of death is said to be cast by a dark shadow of "umnyama". "Umnyama", when used metaphorically to symbolise death, can be translated as "pollution". Pollution, then, is viewed as a marginal state between life and death." (Ngubane, 1977 : 78). "Umnyama" as a mystic force diminishes resistance to disease, and creates conditions of bad luck, misfortune - "amashwa", and "isidina" - repulsiveness. "Umnyama" is contagious. Those in a state of "umnyama" are said to "zila". They have to withdraw from social life, speak in low tones, abstain from pleasurable experiences. Those who await the burial with family - relatives and neighbours, the community that attend the burial, also get "umnyama". On the day or day before the burial, a beast is slaughtered, so that its "umswani" - stomach contents are added to the water, for "ukugeza" or "ukuhlamba izandla", that the washing of hands "isiko" (Ngubane, 1977; Raum, 1973).

This custom of "ukugeza izandla" or "ihlambo" is still performed in both rural and urban Zulu speaking communities. It is done twice, on day of burial, and three months later when the "ukuzila" cloth or string is removed. "Inzilo" is the sign of "ukuzila" - mourning. The shaving of heads - "ukugunda ikhanda" is also done by men and children, but a married woman shaves her head when her husband has died. "Ukugunda" is often done with the first "ukugeza izandla". The slaughtering "isiko" is also necessary for the wandering spirit of the dead, that is "isithunzi", so that it can be turned into "idlozi". This is important because it is only the "amadlozi" who can bring good luck to the family and protect them. (Ngubane, 1977; Krige, 1965; Raum, 1973).

The family of a patient who has died but has a complaint for instance, the patient's property, return after three months to lodge that complaint. This is often irritating to the hospital staff, as the time factor is crucial in determining success of such an investigation. It is only when the caregivers understand that the family has to withdraw from social life and avoid arguments, that they will avoid scolding them for coming so late. The researcher was indeed faced with a complaint dating three months back in November 1986, about a patient alleged to have not been cared for properly in out-patients' department. The complainant was a practising christian, well educated man - holding a university diploma, a shop-owner, and married to a nursing sister in Northern Zululand. He told the researcher he had to await the second "ukugeza izandla" and remove the "inzilo", before coming to lodge his complaint. The fortunate part was that he could give the exact date and that it was the night nurses that dealt with his mother. So, in fifteen minutes time the file was available, and the medical superintendent and myself answered all his queries, and he went home happy. The delay, however, could as in the same case does make the settling of complaints difficult.

### 3.6 THE NURSE IN CONFLICT

The Zulu nurse often finds herself in conflict with the self/her culture and medical and nursing science. There are times when the patients question the nurse about their illness and comment in terms of Zulu cultural beliefs, linking them to and comparing them to their diagnoses. To take an example, it might be easy for the nurse to convince a patient about cellulitis caused by an infected wound, where Zulus also know the gland in the groins swells up. On the other hand

cellulitis without an obvious wound, is according to Zulu beliefs caused by sorcery or angry ancestors, and the nurse will find it very difficult to convince the patient about the pathological cause. In actual fact, the patient feels the nurse is a hypocrite or has become distant from them by discarding her cultural beliefs.

At times the nurse finds herself acting as a middle-man, mediating between medical/nursing science and religious beliefs either Zulu or christian. The dying patient might call for a pastor to settle his spiritual problems with all that done, the same patient might again request a pass-out to go and slaughter for the ancestors - to appease them and ask for a speedy recovery. At times, the patients want to go and slaughter to make peace in relation to family disputes/conflicts, or quarrel with a neighbour, or rid themselves of some pollution - "ukugeza umnyama", from the previous death in the family. The settling of dispute - "ukuthelelana amanzi" - there is practical "pouring water for each other" and hands are washed as under a running tap. This is done outside the fence so that "umnyama" does not come within the family.

These are of course some patients who fully subscribe to the germ theory and hold "pure" christian values. There are some patients who say it openly that they come to hospital because they need a medical certificate to secure their jobs. There are some patients who believe that Zulu cultural treatment or observance of customs and medical treatment complement each other. In other words, they believe that a Zulu is different from a White person although they may be suffering from the same disease, and that is the reason for starting with an

"isangoma" and then going to the "inyanga", only when these healers have failed do they then come to hospital. This has been experienced by the researcher since 1958. Of course, the reaction of Western doctors to this procedure is that of extreme irritation. They believe that there would have been a far better chance of effecting a cure if the patient had come to the hospital early on in the course of the illness.

### 3.7 IMPACT OF DEATH UPON NURSES AND OTHER CAREGIVERS

As a nurse who has nursed the dying I proved that it is a testing and emotionally demanding experience. It is, indeed, the nature of this experience which led me to choose death and dying as the topic for this dissertation. In addition, I have long felt that not enough attention is given to both the emotional side of the experience of the patient and family. It may be that in joining in the mourning ceremonies for the patient the nurse can herself receive some degree of comfort and support.

I must stress that it is not merely my personal experience of nursing the dying patients which leads me to make this suggestion. The literature attests to the real problems encountered by caregivers be moved over in the face of death of patients (Glaser & Strauss, 1964). In caring for the sick, each patient becomes known as an individual, relations develop, which bring sadness and loss, when severed by death (Parkes, 1975).

Nursing and medicine are meant to be with compassion and when the patient dies, his nurse and doctor too, grieves for the loss. They

get a sense of dreadful emptiness. They feel tired, miserable and defeated (Oerlemans, 1972).

In the next chapter the researcher gives her own Zulu cultural background and perceptions of death and dying which she took along to nurse training and her nursing experiences of dying patients since 1958.

## CHAPTER 4

## THE RESEARCHER'S NURSING EXPERIENCE RELATING TO DEATH AND DYING

## 4.1 INTRODUCTION

I grew up at KwaMondi Norwegian Lutheran Mission at Eshowe. Originally under Chief Mpungose, this mission was demarcated and handed over to the missionaries in 1861, for them to live on with their converts, who became known as "amakholwa" or "believers". The first missionary was Rev. Oftebro and Chief Mpungose, who was not a Christian, nevertheless allowed the "amakholwa" to elect a chief from amongst their own ranks. This enabled them to strengthen their Christian culture without his interference. (Burger, 1934; du Plessis, 1965). So, there was, and still is a very strong Christian influence in the area, and I was reared in this tradition.

We did, however, meet the traditional people/"amabhinca" in the outlying areas of the mission. Some even came to worship at the mission on occasions and their children attended school with us at KwaMondi. In our homes, at Sunday School, and at school we were taught to respect and accept "amabhinca". My parents had also been brought up on the mission stations - my father at the Clermont Lutheran Mission called Christianenberg and my mother at the Ongoye Lutheran Mission. My mother and her two sisters were actually reared in the home of a Norwegian missionary, Rev. Audensgard (Snr) and his wife, from the age of one year until she got married, as they were orphans. My father's parents had settled at KwaMondi when my father was twelve years old. So, my father's in-laws and our maternal grandparents and aunts and uncle were the Audensgards.

Although I grew up in a family within a Christian environment, there were traditional customs and practices that were carried out in the neighbourhood and also at my home. To quote a few, twenty-first birthdays were celebrated, but it was not just a cake which was eaten. There had to be a goat slaughtered according to the traditional initiation or "ukwemula" ceremony. "Ilobolo" or bridewealth, had to be paid, and if the young woman fell pregnant before marriage, a beast

had to be paid by the man's party and it was slaughtered to cleanse the girl's peer group, and the "isigodi" (locality) of pollution, or "umnyama" as the Zulu say. At the same time, the unmarried mother was excommunicated until delivery, after which she would attend the penitent class and then be reinstated as a church member.

So I grew up realising that there were Zulu ways of doing things which were good - good in a sense that I did not think they were contrary to Christian values. On the other hand, I also grew up knowing that in the case of a slaughtering to the ancestors, for instance, the missionary was told that it was a party, and not a customary function, or else he would not come to bless the occasion, and also the head of the family would be ex-communicated.

When I attended the confirmation class in 1952, we were taught about life after death, and the remembrance of the dead which was referred to as worshipping the ancestors, was strongly condemned. I questioned the Norwegian Missionary why they (missionaries) always went to the graveyard on almost every Sunday afternoon. He said that it was because they loved their late fellow missionaries who had died, and in remembrance went to put flowers on their graves. I then asked him why they, as missionaries, assumed we worshipped the dead, when we made a feast to remember them. He became offended and reported me to my father on Sunday. My father told him that I also asked him a lot of questions like what happens to the stars during the day, why was it cold in winter, and so forth, and advised him to answer my questions, but he never answered that particular question.

#### 4.1.1 Ideas About Death:

Death in my understanding, was when a person was called by God. As a child my little sister died when I was five years old. My father and mother emphasised that she had gone to Jesus, and that I would never see her again. I can remember well the first and second washing of hands ceremonies ("ukugeza izandla"), performed when my paternal uncle ("ubaba omdala") died in 1950. I learnt at that time that it was to

cleansed off the pollution - "umnyama". As I grew older I learnt more about the pollution which Zulus believe is caused by death. I also learnt that it was the adults who deal with a corpse and not young people, whom both Christians and traditional people shield from death. Children of about ten years are allowed to see the corpse of a relative before it leaves home for the burial, but only in a hurried and confusing way. As children we were left wondering whom we had seen, after being "pushed in and out" of my grandfather's bedroom, when he was in the coffin, in 1951. So, death and all things pertaining to death was the world of the adults.

It was common on our mission for the youth after high school to take up teacher's training or to become clerks at the various government or private institutions nearby. Nursing was frowned upon. The stigma attached to nursing was associated with dealing with the dead. It was believed and we all accepted it as a well known fact, that orientation to nursing included being made to sleep in the same room where a corpse was laid out. It was said that this ensured that the young nurses learnt to be brave.

This belief I suppose must have grown out of the disbelief and wonder as to how young girls could handle corpses in the hospital situation, when they had never done it in their homes and community. It was imagined that there had indeed to be some kind of hard and inhumane initiation to enable a young girl to acquire the bravery to actually handle a corpse, a duty which was feared even by elderly women.

In 1946 my eldest sister applied to do nursing. So, obviously, reports were sought on her by the hospital, from where she had been schooling, before going to Inanda Seminary, where she was doing standard eight. The then principal of KwaMondi approached my father, to find out whether he would actually allow his daughter to take up nursing. The principal mentioned the belief that she would have to sleep next to a corpse. My father dismissed all that as myths, and my sister went for nurse training in 1947.

My father had wanted his youngest sister to be a nurse. He had arranged for her to go to McCords Hospital, in 1932, but his mother was against her daughter taking up nursing where she would handle corpses and be polluted. My father was working at Mtunzini as a policeman and returning to KwaMondi every weekend. When he returned home on a weekend prior to the Tuesday set for Aunt Chester to leave for McCords, he did not find her at home. My grandmother had sent her to Nkandla to take up a teaching post. That had caused a lot of ill-feelings between them, and he was only left with a hope that one of his own children would take up nursing.

My father wanted me to be a medical doctor. He was himself a part-time herbalist. I preferred teaching, but felt I could not disappoint him. Then things went wrong. When I went to high school education at Mariannahill there was no vocational guidance, and I took the wrong subjects. This was realised only in the second semester of my standard eight. I was not prepared to go back to standard seven. I therefore went for teacher training. Thereafter, I was a school teacher for a year and a half but decided finally to take up nursing. I realised the problem of married female teachers who could not readily find employment, after they had resigned to give birth, as their conditions of service did not provide maternity leave, and nursing did. I was thus finally following in my sister's footsteps.

My father had learnt some traditional ways of healing from his father. This motivated him to undergo a correspondence herbalist course in the 1940's. I think this was a way of improving what he had learnt from his parents. My father was educated and had passed standard six in the 1920's. He worked as a policeman, and later as court interpreter. He told us that their English text book was called the Royal Reader. At that time passing standard six was like passing matric these days. As Black education advanced, people of my father's generation were simply referred to or nicknamed as the "Royal Reader". Even today elderly men in their 70's who speak good English are called "Royal Readers". There are a lot of "amakholwa" who were at the Mission Stations, like my father who were also exempted from some of the restrictive clauses of the Native Law.

#### 4.2 FIRST ENCOUNTER WITH DEATH AS CADET/TRIAL NURSE

I commenced nursing on 1 July 1958, at King Edward Hospital, as a trial or cadet nurse. We came as a group of eighteen girls. We were allocated to the various wards, and I was allocated to a female surgical ward. I always worked together with another junior nurse, who had passed her first three months of training. Her name was Shirley. We were mainly messengers and gave basic unskilled care to patients - feeding, turning, bathing, changing soiled linen.

On the second month as a trial nurse, I found myself assisting Shirley with the laying out of a corpse. She simply called me to behind the screens. She signalled that I should not talk. When entered behind the screen, she whispered "The patient has died and we are to wash her, dress her up, and take her to the mortuary. Sister "Blondie" must not hear us talk or whisper over the body". There was no response from me, and after all she did not need it. (Blondie was the nickname for sister in charge of the ward). Shirley gave me a nurses' gown to put on, and a mask.

A silent bath ensued, followed by plugging of orifices with cotton wool, and then dressing up the corpse with a white shroud. The hands were tied together clutched as in prayer. The mortuary labels had been completed by Shirley, and one was fixed onto the neck, with the aid of the shroud strings.

As we did the procedure I wondered what made the body so stiff. I also tried to recall what my baby sister looked like when she had died at nine months in 1943. I could not. I tried to recall my grandmother and grandfather when they had died in 1951 and 1952 respectively, but I could not. I wondered where the patient's soul was. I even wondered whether I was going to be made to sleep in the mortuary. I thought the mortuary was just a certain ward or sideward as I had never heard the word "mortuary" in my life. The label for the corpse made me wonder why a human body could be labelled like a parcel for postage. It undermined human dignity, as far as I was concerned.

Shirley signalled that we remove gowns and masks. When we were outside the screen, she said I must bring a dirty linen runabout. As I emerged from the sluice room with the runabout, there was the mortuary porter with a very funny stretcher. It just had two big wheels and a frame over it. Shirley led him to the bedside. I followed. We put on our gowns. The three of us lifted the corpse onto the stretcher. We assisted the porter put the top frame on the trolley, and put the white canvas cover over the frame. The canvas had a red line down its centre and across at its upper third - which formed a large cross.

The porter wheeled out the body and stopped just outside the ward's main entrance. Shirley and myself quickly stripped the bed, removed our bathing equipment, and lastly the screens, to the sluice room. The patients next to this bed had turned their heads away, and covered their faces with their top bedsheets. We then proceeded in a silent walk to the mortuary. Shirley walked with dignity, in her pink uniform, in front at the side of the trolley. I walked behind Shirley mid-way the length of the mortuary trolley. I had a complete view of the red cross. I wore a white uniform with a red collar, short sleeves edged with red. My mind recollected the journey of the Lord Jesus to Calvary. I think this thought was evoked by the experience I had, at St. Francis' College at Mariannahill, where on Easter we had a procession depicting the seven words of Christ's on the cross, in the form of seven stations of the grotto masses. I recalled remaining at home with my siblings, as my grandmother's coffin was carried out of the house, by four men as pall-bearers, walked in front followed by the adult family members and the neighbours to the graveyard.

Our journey to the mortuary seemed very long that day, as compared to later trips to the mortuary. When we met the staff on the way/corridor they stood still or reduced their pace, kept on the left and kept silent until we had passed. We reached the mortuary entrance, entered and the porter opened one refrigerator door. I closed my eyes at the sight of all those corpses. I said a short prayer, "Lord help me to be brave". We put the corpse on the shelf. Shirley made an entry in

the mortuary register, and hung up the second completed label, on the number corresponding to the shelf on which we had put the corpse. It clicked in my mind why the corpse had to be labelled, as there were so many. O! But the sight of those numerous corpses I saw, in that refrigerator, made a lasting impression in my mind.

Shirley assisted me with the next two layouts. She then told me I had to do it alone thereafter, and I did. I started off a bit shaky, but I was steady by the time I finished.

#### 4.3 PRELIMINARY TRAINING SCHOOL (PTS) THEORY AND PRACTICAL : LAST OFFICES

I was a trial nurse from 1 July to 14 September 1958. On the 15th September we went to the lecture rooms, as PTS nurses. We had lectures Monday to Friday. On Saturdays we went to the wards. We were given between 09h00 - 13h00 off duty. We returned on duty at 13h00 up to 20h00. On Saturdays now and again one would come across a layout.

At the beginning of December, in the last two weeks of PTS, we were taught the signs and symptoms of dying and death. We learnt and recited these. We had a practical lecture on doing a layout, using a dummy in the demonstration room. The sister was silent right through the procedure and did exactly as Shirley. She stressed that any nurse who could be seen or heard talking over a corpse during the layout, or on the way to the mortuary would be dismissed immediately.

When we were on our dormitories, that day, we discussed about this sudden exposure to death, when we were so young. We felt it was so contrary to our culture that we dealt with corpses. We felt it was as good as being made to sleep in the same room where a corpse was kept. My colleagues who had been orientated by the male orderlies to doing a layout during trial nurse period, found the sister's method very different. They had often not bathed the corpse. They had used the cheatele forceps (enormous instruments used for holding bowls) for plugging orifices, not the orange sticks as sister did. I was happy Shirley had taught me the correct method.

#### 4.4. EXPERIENCE WITH DYING PATIENTS AS A STUDENT NURSE

Once we had passed PTS we were referred to as student nurses. We were allocated to the wards, armed with knowledge of only the signs and symptoms of death.

In my first three months of second year I worked in the male surgical ward. On the corner bed of the ward verandah lay a man called Alfred. He was very ill, with wounds all over the back and legs. He had a very offensive smell, his sores full of maggots. He lay on a plaster of Paris frame, which had been specially made for him. The frame provided a hole opposite his buttocks. It was, therefore, possible to offer him a bedpan, without lifting or hurting him. The senior nurse, Nomvukelo, used to dress his wounds. I often fed this patient. So, each time Nomvukelo wheeled her dressing trolley to the verandah, we as junior nurses would pretend to be very busy. Despite that I was often caught up in assisting Nomvukelo, as I was with feeding Alfred. So, I ultimately examined my conscience as to why I allowed myself to be lured off by the gang spirit. I remembered my mother's counselling words when I left teaching for nursing - "Joy, my child, you have chosen a very critical and delicate profession. Be careful in your caring of patients. One time a patient will ask for water. You might ignore or forget to give that patient water. Later, you might find out that it was the patient's last request on earth. That will leave you with a bitter conscience for ever."

I, from that day made Alfred my special concern. When I came on duty I went to greet him. I informed him when I was going to be off. One day he told me that when I was off he was not fed and not washed. I was so junior to tackle such a problem. I urged Alfred to report to the male registered nurse in-charge. Alfred told me this man hardly checked on the patients on the verandah part of the ward. He added, that he was just telling me as his mother, that in case I am around on my day off, I could pop in to see him. I felt tears hot in my eyes when he said this.

Alfred never had visitors. His request was very genuine but if I had to come and see him when I had my day off, it meant getting permission from the matron's office. It meant putting on the full uniform. It meant explaining the relationship with the patient for matron to decide whether to grant me permission. It meant a thorough check by colleagues and rehearsing what you would say when in front of the matron. We knew that despite all that rehearsal, the matron would still find something wrong with you. It could be a tight belt, or short uniform, or too long a uniform, too much make up, or whatever. With all those obstacles in my mind I preferred to go off late in order to feed Alfred, particularly when I was off duty at 17h00. On my day off I would sneak into the ward, in uniform, with the nurses from the first supper i.e. at 18h30, to see and feed Alfred.

I had problems with feeding Alfred when I was to be off at 17h00, and rushing for a 17h15 film at the cinema at Grey or Victoria Streets with my boyfriend. This was not common as I did not often go to movie shows. However, I enjoyed Elvis Presley, Pat Boone, or a religious topic and would take the risk of being late. I would struggle to get the porridge early - even if it meant stealing it from another ward, to feed Alfred. One day, I remember reaching the cinema at 17h45. When my boyfriend asked why I was late I said, "I was delayed by Alfred." He saw red, asking who was Alfred. He cooled off when I briefly said, "He is a very ill patient, with an offensive odour, and the "gang" is dodging feeding him. Should I have left him to starve the whole night?"

One day as we dressed Alfred's wounds with Nomvukelo, the smell was so bad that I felt nauseous. I put down the leg I was holding and rushed to the bathroom, as I felt I could not hold the vomiting reflex anymore. As I bent over the bath to vomit, I heard a voice "Joy, what are you doing?" I stood up and the nausea disappeared. I recalled my mother's words. I quietly said, "God forgive and help me."

I briskly walked out of the bathroom. I met a nurse sucking a sweet. I asked her to offer me one and she did. I sucked it and went back to Alfred. Alfred, with his faint voice said, "I wondered who was to

assist Nomvukelo when you left!" I just said, "Don't worry Alfred, I am back." I continued to enjoy my sweet and never felt nauseated by his offensive smell again, or by that of any other patient, up to this day.

One day, I thought of talking to Alfred about his future. I plucked up the courage to ask him whether he had any hope of recovery. He said he did not. I asked him why he did not ask the Lord to relieve him from the pain and suffering. He said that he had sinned before God. I asked him not to enumerate his wrongs on religious grounds. I asked him whether he wanted a pastor. He agreed and did not mind which religious denomination. I phoned my pastors on a Friday, at Milne Street and at Moore Road, but they were not in. I went back to Alfred to inform him about my failure. I reassured Alfred that all he needed was to pray, and tell God what he had done wrong, ask Him to forgive him. I prayed with Alfred before leaving him. I was to continue to try and find the pastor.

On Saturday the visiting hour was at 14h00 - 15h00, I saw the Methodist men in their church uniforms coming from the opposite ward. I approached their leader and invited them to assist Alfred. They followed me as I led them to Alfred's bedside. He smiled as I introduced him to them. They sang hymns and unanimously prayed. It was surprising to hear Alfred's voice stronger than all of those christian friends. When they had left I went to feed Alfred before going off at 17h00. Alfred was extremely happy. His face was shining as what I imagined was like the glorification of Christ on the mountain. This shining light formed a ring around his face. This type of shining light has been revealed to me on a number of occasions with a reasonable number of patients that were dying during my years of nursing.

On the next day I was off duty. It was a Sunday. I left the Nurses' Home early to visit my eldest sister at North Street, and to proceed to the 15h00 service at Moore Road. When I reached the Nurses Home at about 17h00, I was met by nurses who were returning from duty, who told me Alfred died at about 10h00. They told me he had wanted me to say

good-bye, but I could not be found at the Nurses' Home. They told me he told them to thank me, but they said I shall hear the details from the male nurse in-charge. I accepted Alfred's death quietly. I, however, blamed myself that I did not go to see him in the morning.

On Monday I went on duty. After taking the report from the night nurses, I was called to the duty room by the male nurse in-charge. He told me that Alfred was very grateful for my care and concern about feeding him, assisting Nomvukelo, and above all, the spiritual help. He felt he would see the Lord because of my help. He felt if I continued to care for the patients as I did, I would be successful in my nursing career. The male nurse in-charge also thanked me for having assisted this patient. He said Alfred said he must shake my hand for him and say, "God bless." I was happy and thanked Mr X.

During my nurse training days I assisted a lot of patients who were dying - praying with them and finding them pastors to settle their spiritual problems. The Catholic priest was always in the hospital. He traced all patients of his faith from the clerks' admission register every morning. He visited them in the wards. So, those who required the last sacrament had no problem. After hours he was on the line, and was called when required.

Out of the dying patients nursed, Alfred still lives in my memory and his visual image is still very vivid in my mind. I think it is so because it was through him that I experienced discussing death with the patient. I also feel it was through him that I "passed" to tolerate an offensive odour and experienced the trust, confidence, and faith a patient could have in a nurse. It was amazing how he could even hear my footsteps even if I walked in the ward in section two, opposite where he lay on the verandah.

As a student midwife I baptised a lot of dying babies and premature babies. I was teased by my colleagues that I was suitable to be a pastor's wife. I hardly saw or met a maternal death during my midwifery training.

The bereaved family was always spoken to by the sister in the duty room. We only heard how she spoke to the family if we as juniors happened to assist lift a collapsing relative to the duty room. There was often wailing by relatives, particularly women - both Black and Indians. The wailing was worse when a husband had died.

During our nurse training we saw observance of traditional and religious rituals performed. We never did a layout of a Moslem as the body was collected immediately after death - when doctor had certified the patient dead. The relatives of Black patients came with the ziphuf-mucronaea twigs to take away the spirit of the deceased.

One experienced relatives of the deceased refusing to sign consents for post-mortems. The doctor would just be firm that if they did not sign, they would not get the corpse because he could not guess what caused the death of the patient. The relatives would plead and plead, until they signed the consent. Their argument was very simple, humble, and traditional - is it going to bring him to life again? At times, it needed a family opinion and discussion in a traditional manner. But then, the family would be far out in the rural area, and relatives left behind would be digging the grave, which cannot be left empty overnight. One would sense their bitterness and agony in signing that consent. Some educated and civilised relatives verbalised that it was the unjust laws of this country, that Blacks were used as guinea pigs. I must say that whilst on nurse training and as a registered nurse, I never saw such an argument about consent for post-mortems with Indian relatives. I cannot guarantee it did not occur, though.

As students we learnt that the nurse notified the death and the doctor certified the death. The corpse was left for an hour before the layout was performed. In most cases rigor mortis would have set in. The identification of the body and the safe keeping of the deceased's valuables was strictly adhered to. We never saw a dying patient who had given consent for organ donation.

#### 4.5 PERCEPTION GERM THEORY, OPERATION, INVESTIGATIONS AND CANCER

The cause of illness being pathogenic also caused a lot of uncertainty in my mind, as for other Zulu nurses. It was a difficult fact to conceptualise, particularly as we could not see germs. At times we would speak about these germs in the dormitory. We even made fun of it, and called germs "James", in fun of that they were alive. We likened it to the amoeba "story" as taught at high school in biology. We would compare illnesses of patients to those we had seen or known before commencing training. We would relate to each other how the witchdoctors successfully treated some illnesses. I would also tell my colleagues that my father underwent a part-time herbalist course, although a court interpreter, and what he could treat - urinary tract infection, how he made a hot fermentation for an abscess from soap and sugar paste and how he drained it using an empty wide-mouthed bottle as a suction. As we went on with training one was able to identify similarities in medical and traditional remedies, like the inhalation for nasal congestion. That gave me pride that my culture had some good remedies. I still hold that Zulus have a complete traditional health care programme.

I only saw germs under a microscope when I was a teaching sister. I went with a group of students to King George V Hospital, to attend a practical health education lecture given by Dr Molly Walker to patients suffering from pulmonary tuberculosis. Her approach emphasised that both the nurse and the patient have to be convinced that pulmonary tuberculosis is caused by a germ. She stressed that in health education the "germ" should be interpreted as the "seed of disease" (imbewu yokufa) to emphasise that it "germinated" once it reaches a suitable media in the body. The Zulu word often used for "germ" is "igciwane"/ash particles - which is lifeless, and it makes fun of the germ theory. The nurse and the patient had to see the tuberculosis germ under the microscope. It was the most significant day in my nursing career - to see the germ. This was in 1970, in the twelfth year of my nursing career.

I have also noted in my nursing career that the Zulu translation of operation is "ukuhlinza"/skinning - in the sense of skinning a slaughtered beast. The anaesthetic is referred to as the injection that "kills"/"umjovo obulalalayo". It is understood though that the person "wakes up" after the operation. As one matured in nursing, the fear of an operation associated with the term skinning was realised. One would then choose one's words in explaining the intended operation, particularly to apprehensive relatives, and say that the doctor intends to open the patient, "udokotela uzokuvula". They would, however, exclaim and say, "Nurse, you mean doctor wants to operate/skin him?" Of course, most of the operations are performed, with the consent of the patient and relatives. It was just rare occasions that the patient or the relatives signed refusal hospital treatment. There are some of those, that the researcher felt the doctors wanted to operate for the sake of operating - where the patient is too old and I felt she/he should be left alone to "goduka" peacefully. Relatives always expressed their delight and gratefulness for a successful operation. They always verbalised that they were to tell their families and neighbours about the capabilities of medical and nursing professionals.

The medical approach to treatment became strange to me, as a junior nurse, in that the patient could stay for days before treatment was initiated. But as one grew up to be senior, this was well understood and could be explained to the patient, that investigations were being done. Up to my present days of nursing, some patients complain if they have to wait for a few days, before commencing treatment. They express their discontent that it seems they are admitted to just eat the hospital food.

I first heard of cancer when I started nursing - and to be exact it was in 1959. I was a first year student, and heard senior student nurses on night duty speaking of the night matron who had had a mastectomy done. I gathered from their conversation that the cancer was incurable. I tried to imagine what cancer was in Zulu, and what a patient with cancer looked like, and felt, suffering an incurable disease. As I grew up in nursing I met and nursed patients with cancer. I think it was just in the late 1960's that I got to know that

cancer was referred to in Zulu as "umdlavuza" which means destructing/devastating condition. It is now well understood by the Zulu community that cancer is incurable. Some understand that medical treatment can prolong ones life. I could say it is one of the most feared diseases. There are some herbalists on the South Coast and in the Transkei who claim that they can treat cancer. Patients have left hospital, refusing an operation and radium therapy because the herbalists that treat cancer say that such treatments inhibit the effectiveness of their herbal treatment. One has in practice seen some of these patients return with advanced cancer and in the terminal stage of illness.

#### 4.6 EXPERIENCE WITH DYING PATIENTS AS A REGISTERED NURSE

##### 4.6.1 Clinical Area:

The love and concern of assisting the dying patients continued. I had an advantage then of being able to find the pastor for the patient as I could phone from the ward. I developed intuition of a patient who was going to die, but with some, it was that ring of light. I would then act immediately to find a pastor. For some patients, I neither had that intuition nor saw the ring of light.

After completing midwifery training in 1963, I worked in a male surgical ward. A pensioned pastor from KwaMondi took ill whilst visiting his daughter in Durban. He had problems with his urinary system and was diabetic and hypertensive. He was very ill, and became unconscious from either a hyperglycaemic or hypo-glycaemic coma. His wife (a retired school teacher) came the next morning, on 28 September 1963 and asked me, "How is he?" I said, "He is critically ill, and we can expect anything." As I spoke to her the doctor came and joined us. He told the wife clearly that he had been awake the whole night trying to stabilise his sugar. It had just come right, and the patient was awake then. He concluded, "Mama, I do not say I have cured him. His chances of recovery are very limited." The old lady looked at us and said, "Doctor, he is going to survive. He cannot die today, it is his birthday!" She walked off to the patient's bedside, and said in

English, "Hallo, my dear! Happy birthday!" She kissed him. O! The patient got so excited and sat up in bed. We had followed her to the bedside. We also said, "Happy Birthday!" to a person we had thought was dying. In three days time, the patient was discharged. I saw what the family support of love and faith can do in a state of helplessness.

I always felt confident to talk and pray with a dying person. Some gave me messages to their families. My mother's counselling always lived in my conscience. It was common that patients transferred into our hospital were from very far. They never had visitors and often appeared very lonely. During the visiting hour, we as nurses would sit next to their beds and roll bandages, or fold gauze dressings, or make cotton wool swabs. At times we assisted them by writing letters home on their behalf or giving them paper to write for themselves.

I had a lot of dealings with the bereaved families as a registered nurse. At times they wanted to know how the patient died - peacefully, any messages, any struggle. One told them what could comfort them, such as having been seen by a pastor, the acceptance pending death or giving them the messages. The relatives were always grateful for the help and assistance and relatives sent "thank you" cards or wrote letters.

The 1964 Effingham train disaster (involving a train transporting workers to KwaMashu Township after 17h00) happened when I was off duty and away from the hospital. The patients admitted were a very minor percentage of those that died in hundreds. On a Saturday morning of that week, as I went on duty, I turned to look towards the mortuary. I saw two huge trucks packed with coffins to their rail brim. I was so shocked that I stood still for some seconds. That scene spelt out the extent of the disaster. I expected to find the ward teeming with floor beds, even perhaps in the passage towards the lifts. To my surprise there were no floor beds in the passage. There were about six disaster patients on skeletal traction, and about ten others. None of them died in my ward.

I then worked in maternity in the labour ward or ante-natal clinic. Thereafter, in the out-patients department, then fevers, paediatric ward, then went to the nursing lecture room/college.

#### 4.6.2 Nursing School : Teaching About Death and Dying:

At that time, in 1966 and up to 1969 the nursing curriculum did not include the social sciences. The topic of last offices appeared only in the theory of nursing and practical. So, the teaching sister who was not a qualified tutor, handled this topic. The tutor training programme included psychology and sociology. The lecture contents were the signs and symptoms of death, that the dying patient be placed in the sideward, that the most senior nurse in the ward remains with the patient - to moisten lips and keep the patient comfortable. The relatives were to be notified and made aware that the patient was dying. They were to be allowed to remain with the patient. The student nurses always grumbled or had an outburst of laughter when one stated that the most senior nurse remains with the dying patient. I never asked why they had that reaction because I fully understood what I and they were experiencing in the practical situation.

It often happened that when I demonstrated laying out of the body that some student nurses would cry. The psychological reaction was understood and nothing was said to them. They often settled and collected themselves before the demonstration was over. One was also not equipped with knowledge of assisting nurses with such reactions. The educational psychology I had done in teacher training was related to school children and the school teacher.

#### 4.6.3 Experience Death And Dying As Nurse Administrator:

I became a nurse administrator in November 1976, at Ngwelezana Hospital. Although I was deputy matron responsible for staff administration, I also relieved other matrons and supervised the intensive care unit. I had been detached from active patient care since March 1966. By being detached, I mean I only went to the ward with student nurses to demonstrate or supervise certain nursing skills,

for just limited periods. At those intervals I often found that spiritual care was not given. The nurses in the intensive care unit were sensitised about spiritual care of patients and they responded very well. The unconscious, pending death patients, if Catholic received the last sacrament. The other patients would be assisted with prayer and/or calling the pastor if they could speak.

Towards the end of November 1976, on a Saturday afternoon, I was the only matron on duty to supervise the nine wards and out-patients. At about 15h20 I went to supervise the last ward which was the male surgical. I saw a critically ill patient with cancer of the penis. As I looked at him, I had that intuition that he needed spiritual care and that he was dying. I did not say anything to the patient. As we went out of the ward I asked sister whether she had assisted him as he was dying. Sister asked me what type of assistance I meant. I told sister that I meant asking him how he felt about his condition, or whether he needed a priest. Sister said, it was difficult to initiate such a discussion with such an ill patient. I happened to know that this sister was a Lutheran and I, therefore, reminded her that we are taught during confirmation classes how to assist a dying person. She did not deny it but said she was afraid.

I rushed back to the office to prepare for handing over the report to the matron coming on duty at 15h45. The patient's image kept on flashing in my mind. I recalled my past experiences, knew what it meant, and went to the ward. I found him sleeping facing the wall. His face was so bony and arms so thin. He tried to turn but was too weak. I assisted him to turn and sat next to him. I asked him again how he felt and he said he was too helpless - just dying. So, I asked him whether he was ready to die. He said he was regards earthly affairs, but not spiritually. I asked whether I could help him, or whether he felt he needed a pastor. He said he needed a pastor of any religion, and Holy Communion. I, however, prayed with him and advised him that he should pray in the meantime and tell God what was worrying him, as I did not know when the pastor would come, but I was going to try my best to find him to see him before seven. I dashed back to the office and phoned my pastor. At that time, I did not know any other

pastors. The pastor's wife said he was to return at five that afternoon. I gave her the name of the patient and the ward, and I dashed back to the patient to inform him, as I went off duty.

From my house I could see the pastor's house. So, I kept a check at 16h45, and sure enough I saw his car arrive and after a few minutes, saw him drive off. I then settled down. I did not have a telephone, so it was only on Sunday that the pastor told me that the patient was very grateful. On Monday, when I arrived at the hospital I went to check on the patient, only to be told that the patient died at 19h30 on the same Friday evening.

The next step I took was to find out and compile a list of names of all pastors in the area and their telephone numbers. It was pinned up at the switchboard, and it is there even to this date, and serves its purpose.

My intuition about a dying patient and that ring of light that I see has continued. Since 1981 when I assumed matronship, this intuition got linked up to the report taking. The night superintendent would give a report about ill, very ill and critically ill patients. But one patient's name would be singled out in my mind, at times one reported to be just ill, and would worry me. I will ultimately go to see the patient or phone to find out whether the patient needs a pastor or not. The patient would surely be having a desire to see a pastor. Sooner or later the patient would die after seeing the pastor.

I discussed this intuition with my pastor in January 1986. He encouraged me to persist and never relax in assisting the dying patients the way I do. I did think that I should undertake this topic on death and dying for my post-graduate study. So, when I first met my promoter for this study, I mentioned other topics, but when she asked me to tackle this topic, I readily agreed. In fact, I had been discouraged by my family and colleagues when I spoke about death and dying. So, I ultimately thought I was perhaps funny in my way of thinking.

I was encouraged in pursuing this study when one of the surgeons walked into my office in July 1986 to complain that his terminally ill patients were left to die alone. I went to the ward and assisted the nurses to plan care for that patient, treatment that will minister both to their physical needs and also to the spiritual sides of their nature. As Zulus say, we must treat people as "wholes", not just in the body.

#### 4.7 SUMMARY

Looking back over my life and training as a nurse, I can see that I have been fortunate to have got to know a number of different cultural systems well. First, the christian system of beliefs and explanations for disease and death as I was raised. Secondly, the set of beliefs of "amabhinca" neighbours and lastly, the western medical system with its scientific approach. Each has something to offer and, in nursing dying patients' needs to be sensitive to what they think and how they perceive the situation. Only then can we plan adequate treatment for them - treatment that will minister both their physical needs and also to the spiritual side of their nature. As the Zulu say, we must treat people as "wholes", not just the body.

**CHAPTER 5****RESEARCH METHOD****5.1 RESEARCH QUESTION**

What are the Experiences of Death and Dying of Zulu Patients, Their Families and the Caregivers concerned?

**5.2 STUDY SETTING**

The study was carried out in the KwaZulu Ngwelezana Hospital at Empangeni, in the Lower Umfolozi district. The hospital consists of 753 beds, and has eight adult wards. The researcher is employed in this hospital as a senior nurse administrator. Permission to undertake this study was obtained from the Secretary for Health.

The ten (10) patients studied were from five of the eight adult wards. There was no patient followed home as all the patients preferred to die in hospital under medical and nursing care. As will be seen, the researcher did participate in funeral ceremonies at the homes of some of the patients studied.

The caregivers involved in the care of each patient were often one doctor and a team of five to eight nurses. The family members were often three during the illness, and increased to the minimum of fifteen after death and during the mourning period.

**5.3 CASE-STUDY METHOD**

This method was preferred because "the case-study approach clearly allows the researcher the opportunity to see the individual in his total network of relationships" (Treece & Treece, 1977 : 164)). In this it gives a detailed descriptive analysis of situation (and in this case be active) in which the individual moves. It allows the researcher to obtain a wealth of significant information concerning both the subject and the problem area in which she is interested (Notter, 1974).

The case method was particularly appropriate in this study as dying patients have within a network of relationships built up from his or her family (which has wider societal and cultural ties), the doctors and the nurses - who were also studied in detail and whose actions are described.

The steps that were followed were:-

- (i) Identification of the field study; that is, the hospital wards where the dying patients were nursed.
- (ii) Gaining access to the patients, the caregivers (doctors and nurses) and the patients' families.
- (iii) Establishing myself in a researcher's role by informing all the caregivers in the adult wards. This was a difficult task because I could not distance myself from my role as nursing service administrator. Nurses and doctors continued to see me in this role and I also used it so that patients studied and others received better patient care.
- (iv) Data was collected and recorded immediately away from the patient after each in-depth interview, observation and patient record review.
- (v) Leaving the field of study to give distance between the ward and myself, so as to look at the field as objectively as possible and to analyse the data.

Two patients were studied for an average of two months, at a given time. Then two new patients were selected and studied. While a patient was studied, he/she was usually visited daily.

#### 5.4 PILOT STUDY

A pilot study was carried out in the female ward. The method of collecting data via case method proved suitable. The researcher had, however, to improve her questioning technique to a very indirect approach. The tape recording of the interviews was not acceptable to the patient studied. This patient refused to sign the consent for being a research subject, but gave verbal consent.

#### 5.5 CHOICE OF SUBJECTS

The dying patients selected for the study were adult males and females from the surgical, medical and gynaecological wards. Initially, all terminally ill patients were identified. Their names were written on paper and then one name was drawn. A second or third draw was made if the mental state of the patient selected was not normal. This was done repeatedly so that the researcher was seeing an average of two patients at any one time.

A group of patients in each of the four sections of the ward, is cared for by a team of doctors and nurses according to the medical and nursing process approach which allows for individualised patient care. The caregivers involved in the study were of that team of doctors and nurses who were caring for the research patients.

#### 5.6 COLLECTION AND RECORDING OF DATA AND OBSERVATIONS

Intensive or in-depth interviews were carried out with each of the ten dying patients. The subjects studied all refused the recording of the interviews for a variety of reasons. I participated in the care of

the patients studied whilst observing the nurses. This was most unwelcome to the nurses by virtue of my administrative position. The doctors, nurses and the family members were observed and interviewed - and the interviews were recorded immediately thereafter. The patients' files were read and studied with the view to gaining information about the patients' social and medical histories, condition and progress (as seen by the caregivers and what the patient verbalises) and the patients' medical and nursing care plans.

Open-ended questions were asked and these allowed the subjects to give much informative descriptions of their feelings and experience. The questions were, however, posed according to a predetermined pattern, as follows:-

- (i) Patient
  - previous illness history
  - present illness history
  - perceptions and feelings about the future
  - relationships with family at this stage
  - perception of dying
- (ii) Family
  - previous health and illness history of patient
  - relationship with patient and caregivers
  - perception of death and the future
  - feelings after death of patient
- (iii) Caregivers
  - perception patients' prognosis
  - patients' reaction to diagnosis and prognosis
  - communication and reactions of family
  - response to patients' dying needs
  - feelings after death of patient

### 5.7 LIMITATIONS OF STUDY

- (i) Patients in only one area of KwaZulu were studied, which might limit generalizability.
- (ii) The study only focused on those who preferred to die in hospital and nobody who died at home was included.
- (iii) All the patients studied had been told of their diagnosis and prognosis.

### 5.8 VALIDITY AND THE EFFECTS OF THE RESEARCH

- (i) The researcher's presence created an artificial situation for the caring team. The patients studied received better nursing and medical care than other patients in their respective wards. These patients also received extra care and support from the researcher. With this realisation, all the care and events that happened have been described in the case studies, to maintain validity.
- (ii) There was no subject loss in the sense that no patients refused to take part or withdrew from the study, and that increased the validity of the study.
- (iii) Changes in the researcher herself were evident. I was better able to handle the patient interaction without intense emotional involvement.

## RESULTS : CASE STUDIES

(In this chapter the ten cases are fully described.)

## CASE NO. 1 : MISS THALAZA X.

## INTRODUCTION

Miss Thalaza X., was a 45 year old, unmarried mother of five children. Her first name was Agnes, but she preferred this nickname. She was hospitalised on 29 December 1987 with advanced carcinoma of the urinary bladder. I met her on 4 January 1988.

## ON ADMISSION

The patient's case sheet indicated that she had been admitted in a very ill condition. She had been alert, responsive, grossly emaciated, feeding well, helpless and troubled by **nausea** and insomnia. She was complaining of severe lower abdominal pain. She was aware of her diagnosis and aware that she was admitted for terminal care. She was positive about medical and nursing management. She expressed her worry about her children and the father of the children who had deserted her due to her illness.

## FAMILY BACKGROUND

She was an orphan and had one brother who lived at Eshowe with his family. She had remained at her home at Mtunzini with her lover and their three younger children, the youngest being five years old. She had had a misunderstanding with her lover some years before the initial stage of her illness and he had left her. She wept as she said, "My husband has deserted me since I became ill. He is staying with another woman, not far from my

home, where we stayed." He, however, supported the children. The patient referred to him as her husband right through her illness.

Miss Thalaza's first and second sons were working. The first, in Johannesburg, with the uncle and the second at Pietermaritzburg. She was negative about the first son, as he did not support her and rarely visited home. She was positive and spoke favourably of her second son. He sent her money, phoned to find out about her condition and visited home regularly.

Miss Thalaza's neighbour was her aunt - the wife to her uncle who worked in Johannesburg with her first son. They were on good terms. Her aunt ran a shebeen and was described by her as a very busy woman.

Miss Thalaza made her living from what her second son gave her and the flourishing shebeen she ran at her home. This was expressed shyly, "O! Nurse --- well, I made my living from the sale of liquor and beers. I know that is not good to tell to a responsible, respectable person like you." To that the researcher said, "I understand, but know this, I am not here to judge you." She then relaxed.

Miss Thalaza was illiterate and a Zionist by religion. She was not an active member of her church. She was, however, positive to spiritual counselling.

She had negative thoughts about her brother's wife. When the researcher made a suggestion that she contacts the brother to inform him that she had been hospitalised, she said, "But what is the use of telling him? His wife will refuse him coming here. She controls him (she expressed it in Zulu idiom "pulls him by the nose")."

## THE RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

This was on the 4th January 1988 at 13h25. Having introduced myself, Miss Thalaza was positive to being interviewed for research purposes. She did not see the need to sign the consent, as she felt she trusted me as a nurse. She refused the tape recorder saying it will reveal her identity. She also felt it was contrary to what I had said about confidentiality. To make sure her voice was not recorded, she commanded me to remove the tape recorder from the locker and from the ward. This was immediately done. The patient had a very offensive smell and she was aware of it. She tucked herself in with a sheet. She was pleasant, alert, responsive and attentive. She was very emaciated and appeared helpless and lonely. She spoke with confidence, sincerely and openly. She spoke in a commanding manner.

The locker next to her bed was untidy. there were four closed, labelled disposable tumblers on top of the locker. There was no bench under her bed or that of her neighbour. She expressed her gratitude that I sat down next to her to listen to her illness problems.

## ILLNESS HISTORY

Miss Thalaza had been ill since March 1986. She had vaginal bleeding for three months before seeking medical assistance. In June and July 1986 she visited four private doctors, each recommending hospitalisation after examining her. It was only when the vaginal bleeding became severe in July, that she accepted being referred to Eshowe Provincial Hospital by an Mtunzini private doctor. On admission she was transferred to King Edward Hospital. After assessment at King Edward, she was sent to Clairwood Hospital, from where she went to Addington Hospital for radium therapy for three weeks. She

expressed her frustration at being sent up and down. She was discharged home on the fourth week of her hospitalisation, in September 1987. She saw her illness as a pathological condition.

She had continued being ill, anorexic, coughing, vomiting and losing weight at home. She avoided re-hospitalisation. The family wanted her to come to Ngwelezana Hospital as it was nearer, but she felt she had to go to Eshowe Hospital. She ultimately decided to come into Ngwelezana Hospital on 29 December 1987.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The first time she knew of her diagnosis, was from a nurses' conversation at Clairwood Hospital. She heard them say, "This is a long illness that wastes one, bit by bit. One goes in and out of the hospital. Once you have this illness and radium therapy, you shall never recover. It is a disease that affect all races." "You know that day, I cried, and I could not even eat. I told the nurse who was serving food that I had no appetite. I was so disturbed until the date of my discharge." She sobbed as she said these words.

She further expressed her language barrier between her and the doctor, who was her alternative in discussing her diagnosis, as she described the nurses as unapproachable. She further made a comparison between those nurses and myself, who sits down next to her, and discusses her illness with her. She described this as rare.

On admission at Ngwelezana Hospital the doctor through a nurse as interpreter, told her she had advanced carcinoma and that there was

nothing more to be done for her. Doctor gave her a choice either to go back home or to remain in hospital for terminal care. She preferred hospitalisation, as there was nobody to care for her at home.

I asked her how she felt about that information. She said, "It was painful as it became a reality." Asked why she accepted it as a reality only now, when she had known about it since September, she convincingly said, "O! Nurse I had debated this in my mind and I did not accept it. When doctor said it, I was disturbed, but I felt happy he was truthful. But also nurse, I am finished. I am as thin as a rake. I think doctor is true, who can revive such a person." As she spoke she stretched out her thin arms and scrutinised them, as if they belonged to somebody else.

I asked her whether she felt free to discuss her feelings and thoughts about dying. She readily said, "of course, I am glad to have somebody to sincerely listen to my problems."

There were days on which the patient refused to eat and she told me this was because she felt she was a burden to the nurses when she had to be fed very slowly. There were days she felt she was dying and demanded treatment that would stop or revert the dying process. On the 13th January, she had severe lower abdominal pain and nausea. She complained that she was just lying there, doing nothing. She stated they were given some handwork at Clairwood Hospital. I told her I shall send the occupational therapist to see her. To that she said, "Yes, cousin, do send her to see me. I am really bored of just sitting and not doing anything." On the 14th January, the occupational therapist visited her and said she was too weak to perform any activity. Thalaya had insisted, however, that she leaves the items with her, as she was

going to do something. It was left with her - and collected on her death.

On the 15th January she was very ill and refusing to take fluids. She demanded a blood transfusion. She told me blood transfusion is excellent for regaining strength.

On the 18th January, after a weekend off, I went to check on her at 06h45. I met the doctor, who beckoned at me and then told me, "This patient is very ill and might die at anytime. Please inform the relatives" and he walked away. The patient was anxious. On Friday I had promised her that the community psychiatric team would bring her children. So, before I could greet her, she said:-

P: "Hallo, cousin. Is the sister coming back with my children?"

N: "Yes, she is, and how are you?"

P: "O! Nurse I am just exhausted and weak. I really do not know what I am worth!"

N: "You are worth being Thalaza, yourself, a mother of your children and a child of God."

P: "O! Yes, how true, but I am finished and I do not see making it."

N: "If you feel like that, let us plan for the future."

P: "You mean concerning my children?" She wept.

N: "Yes, let us start with them, as you feel they are the most important."

P: "Well, there is actually nothing else to plan for, as I have no assets.

Their father might care for them - but I think I am convinced he will take care of them. My second son shall help his father. But, cousin, I am in pain - I mean heartache." She wept.

I held her in my arms wiping her face with the face cloth. She held on to me.

N: "Yes, cousin, you should feel like that. One thing good is that you can express how you feel."

P: "Yes, cousin - but it is painful."

N: "Yes, it is. I fully understand. Don't you feel better after discussing it?"

P: "I think it is a wonderful idea - I get some relief. You are helping me. Today I am also going to see my children. O! God bless you."

N: "I am happy you feel helped."

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

The aunt was met on the 18th January. She and the three children came with the community psychiatric team, at 10h50 as I had arranged. She gave a similar illness history, as given by Thalaza. She was aware of the patient's diagnosis, as Thalaza told her when she was discharged from the Durban hospital. She expressed it as follows, "She said she has cancer. O! But she is finished. She is just skin and bones. She needs prayers. She might die soon." This was an expression of total acceptance that the patient was dying.

The acceptance was, however, accompanied by an expression that Thalaza was bewitched. She said, "I hate the person who bewitched her. She was so plump and beautiful. Now she is like this. She will not walk out of this hospital."

There was no discussion of the diagnosis between the patient and her family. When I asked the aunt whether she discussed the illness with the patient, she said, "I just reassure her." This was soon after she had said, "I have not "

got even the faintest hope that she will make it - she is finished." This implies awareness and acceptance of the illness outcome and on the other side, total avoidance of discussing that situation.

In the last week of January, on the 29th, the aunt was pitying the patient for the pain she was suffering and wished she could die. She came into the office and anxiously said to me, "Nurse, this person is finished. It would be better if God released her from such pain and suffering. But the hospital can do wonderful work! At least, you know what to do for her. What could we do for her at home? Just tell me! Let me go nurse!" I noticed teary eyes by the time she finished talking and she just walked out. It was obvious she was upset and not prepared to discuss anything lest she cries.

Thalaza's second son visited her on 16 January and the Sister informed me he was aware the mother was dying. He was quoted as having said, "There is nothing left of my mother. We are just waiting for the day of her death."

The aunt did not return to see her until on the 29th February. She came into my office and she was desperate.

Aunt: "Nurse, I did not hope to find her. She looks and smells terrible."

Nurse: "Yes, she is very sick, but try not to wear that expression of despair when you talk to her."

Aunt: "Yes, my child, I shall try my best. Even our culture stresses that despair kills a sick person."

That was the last encounter with the family. The patient died on the 3rd March.

#### PATIENT'S RELATIONSHIP WITH ALL STAFF

The staff referred to here is the caring team. It consisted of the ward doctors, nurses and the researcher.

#### Doctors:

- The patient's first encounter with the doctor on 29 December was positive, when he told her her diagnosis and giving her an option of either going home or being admitted for terminal care.

On the 29th February, the patient told me that she had a serious matter to discuss with me. This matter was presented as follows:-

"Well, cousin, I want to go to Durban - in fact to King Edward Hospital. You see, there, doctor sees all of us patients in the ward."

N: "Cousin, that is not difficult for me to solve. I shall ask the doctor to see you this afternoon, or in the morning."

P: "O! I shall be grateful, cousin."

On checking the patient's chart there was just the initial clerking by doctor. It was the prescription form that had regular entries for the acquisition of treatment from the dispensary. The doctors were in the operating theatre, so the message was left with Sister. Her response was, "I will ask doctor to see her. O! But what can doctor do for her?"

On the 1st March, I went into the ward at 09h40, to see the doctor. The following discussion took place:-

Nurse: "The patient sent for me and when I came, she complained that doctors do not check on her." All the three doctors laughed.

Senior Doctor: "But I always see the terminally ill patients."

Second Doctor: "I saw her this morning. Is it not so?"

(1) Referring to the third doctor, who nodded and laughed.

(2) Patting me on the shoulder and laughing.

Senior Doctor: "You see, matron, I see all terminally ill. But, ha! You will be lucky if your friend pulls up to next week."

Nurse: "Yes, doctor, I am fully aware of that, but at least she should die happy. Doctors, I am appealing to you all, please see her, even just to greet her and to find out how she feels."

Senior Doctor: "OK! OK! We shall see her, but -----"

He shook his head and mumbled something - sort of grumbling. I got very upset and did not say anything more and left the ward.

At 13h05, I returned to the ward to see the patient. As I approached her bed, she tried to lift up her head from the pillow, but failed as she was too ill. She wore the broadest smile I have ever seen with her. She seemed a bit

disorientated. She expressed her gratitude in an excited manner:-

"O! Cousin, udc---ko---te---la ungibonile." ("the doctor saw me.")

The doctors kept on seeing her on the 2nd and 3rd March, in the morning.

Thalaza died on the 3rd March at 18h00 with a positive attitude towards the doctors.

Nurses:

- \* The patient had during her illness positive, negative and neutral feelings about the nurses. She seemed to make a comparison between the Durban hospital nurses, the ward nurses and myself.

Thalaza was totally negative to the Durban nurses, whom she referred to as unapproachable. She heard them speak openly in the middle of the ward about the plight of cancer patients. The fact that she could not speak to the Doctor without these nurses translating for her, formed a barrier between her and the doctor - from whom she could ask about her diagnosis.

On the 7th January, Thalaza informed me that the nurses in the ward were not polite to her. They were also rough in handling her when they assisted her to the bathroom. She also pointed out that, "Even the tablets are not given regularly, and I think that is why I vomit." Actually, the doctor had prescribed an injection to counteract the vomiting. This had not been communicated to the patient.

From the time of her admission she hardly expressed her feelings and condition to the nurses. On the 9th January I was off duty and phoned from home to find out how she was. The Sister on duty said, "She is better today - no problems at all."

Nurse: "Please, Sister, go and greet her for me and tell her I would like to know how she is. I shall hold on." On return,

Sister: "Matron, she says she is not so well. She has diarrhoea today. She says her radio battery is completely flat and Monday is rather too long to wait. Matron, I am sorry, but this morning she told me she was alright."

Nurse: "Thank you Sister. Tell her, I shall send Nomusa (my neighbour) to bring the battery at the visiting hour, at 14h30."

On Monday the 11th January, she informed me that the nurses reprimanded her for walking alone to the toilet. She was reassured this was a safety measure.

On 26 January the patient reported negatively about the night nurses, who had not assisted her in buying peaches from a vendor and do not check on her. She was also negative about the fact that the patient next to her had been moved to the other section. She asked whether that had been done because she smells. I convinced her it was not because of that, but that patients are placed in sections for nursing and medical reasons. I persuaded Sister in-charge of the ward that she be placed in the first section of the ward. This was accepted. A message was left for the Night Superintendent to watch out for unauthorised selling in the wards during the night. At times she took advantage of nurses lack of observation and used it to escape treatment. On

8 January at 13h15, she informed me:-

"O! Cousin, I hate the drip. At times the nurses keep it on for no reason. As it is now, they have not observed that I pulled it out. You know I pulled it out when I went to the toilet. I panicked when I bled, but I quickly applied pressure.

N: "You must be fed up with the drip, (she nodded) but it helped you when you were vomiting. To avoid any panic, tell sister if you want it removed. You see it was meant to give you injections as well.

P: "I knew you would say that as a nurse, cousin."

Thalaza at times showed concern for the nurses who are overworked. On the 1st February, she was concerned that her neighbouring patient had given a wrong illness history to the doctor, saying that she could not swallow. When the doctor came and saw peels of macumba (tuber crop), he felt Sister had not interpreted correctly what the patient had said. Her good nurse, she said, was scolded for a patient who tells lies to gain doctor's sympathy. She reprimanded this patient when doctor and sister had left.

On the 17th February I went to greet Thalaza at 06h45 as I was leaving to attend the meeting in Durban. When I informed sister I was to see the patient the next day, she said:-

"O, matron she is going to be very difficult today."

N: "Why, sister?"

Sister: "Well if you have been here, she cooperates with us, in taking her

treatment and even food."

N: "She should be alright then as she has seen me."

On the 19th February at 13h20 I met a furious Thalata, who said:-

"Cousin, it is good you have come. Just ask these nurses to give me a bedpan. Just look, (pointing at bedpan), I have been telling them that it is painful to sit on this metal bedpan!"

Sister approached from the sluice room, bringing a plastic bedpan. Thalata with her minimal strength, stretched out her hand, grabbed the plastic bedpan from sister and tried to help herself. I signalled sister not to say anything. I assisted her onto the bedpan - she smiled. She then asked me to wait outside the screen, as she released herself.

Sister: "Matron, she is very aggressive today. She does not want any patient next to her."

N: "Why, sister?"

Sister: "I think she is naturally a fussy person."

N: "Has she been like that in the past two months?"

Sister: "No, matron, but she is a difficult person to nurse."

The patient then called me. We both assisted her off the bedpan. I cleaned her hands, as sister took away the bedpan. Thalata, then relaxed and I assisted her to take her fluids.

On the 24th February, the patient was withdrawn and did not talk to all nurses in the ward. She remained like that until the following week. On Saturday when she told sister she wanted to see me, I was not phoned for. Sister told me:-

"I thought she was mentally confused, but also I thought your husband shall not be happy if you leave him when you are off duty. But her son was here and I thought that would satisfy her. I also think Thalaca thinks she possesses you."

N: "Why, sister?"

Sister: "The way she complains about time and that when you have not turned up. As soon as you come she is happy and for the rest of the day! It is really unbelievable! We both laughed."

N: "Was she happy about the son's visit?"

Sister: "Yes, although I know she has a special place for you in her heart."

Second Sister: "Yes, I also agree with sister. She is even jealous of you talking to another patient."

N: "Anyway, tell me if she wants me, at anytime - day or night."

On the 3rd March, when I visited her at 06h15, she was on the verge of dying. She was feeling lonely and deserted. Her face had no expression. Her voice was shaky, her face so popy and she was awake but kept her eyes closed. When I greeted her, she opened her eyes, tried to force a smile, tried to stretch her hand to reach for my hand. I reached for her hand. She said:-

"I am very bad. I have no strength at all. Tell the nurses I am in pain. They do not come to me." She closed her eyes.

I asked sister for a nurse to remain with her. I prayed for her. I told her I was to go and take the report from the Night Superintendent and would return at tea time, at 10h00. I assured her a nurse was to remain with her. She smiled, and I left. At 10h15 when I returned she was asleep. (She died on this day at 18h10).

Researcher:

As already stated, I established rapport with the patient on the very first encounter on the 4th January. She expressed this as follows:-

"I am happy that there is a nurse, who can sit next to me and talk to me, as you do."

She showed her eagerness, or an expression of anxiety, in discussing her illness, on the second day. Soon after greeting her, she said, "You said you were going to ask me to tell you about my illness, so you want to discuss that with me."

The patient's positive attitude was soon noticed by the nurses in the ward. On the 6th January, a nursing assistant in the ward, said:

N/A: "Matron, are you going to be seeing her regularly?"

N: "Yes. Why do you ask that?"

N/A: "It is because she remains happy, if you have been here. She has only had one visitor since admission, as far as I know.

My visits influenced the nurses' care for the patient. As from the 7th January, I noticed that the top of her locker was covered with decorated paper and there were beautiful flowers. There was no other patient's locker that was decorated. Each day as I came into the ward, a nurse would dash to the patient's bedside, tidy up the locker and provide a seat.

The patient was keen that I meet her family. She expressed this on the 7th January. It was the same date she started calling me cousin. She ultimately explained to me that her "husband's" mother is born Mthembu. From then until her death we called and referred to each other as cousins. On the same date she showed concern about my health. She apparently saw me grimace as I got up on the 6th January. So, on the 7th January, she asked:-

P: "How is your backache?"

N: "Who told you I have backache?"

P: "I saw you grimace, when you got up here yesterday."

N: "Well, it is better."

P: "I was worried it might be worse and have nobody to come to see me."

On the 20th January, I visited her at 07h15 as I was going to attend a number of meetings that day. She was in the bath and happily singing a hymn. She said, "O! I pity you. You must be mentally strained by attending so many

The arrangement to get her children to come to see her, was exciting and gratifying to her. She further opened up to say out her wishes. She asked that the psychiatric sister brings her the radio. She did. The patient expressed her feelings as follows:-

P: "Really, I want you to fully understand that I am very grateful about your concern. To have somebody to talk to is really great."

She told me when the battery was flat and she sent a message when I was off duty for me to bring her "phuthu" and bean soup. She told me when she wanted grapes or chutney. She was free to express her fears, like bad dreams. On the 10th January she told me that she was afraid of falling asleep. I noticed she looked depressed and sitting up but awake. She told me in a low tone and serious manner:-

P: "Really, I am trying not to fall asleep, as you find me sitting up. Each time I fall asleep, I see a host of people, clothed in white long robes, their heads covered with white cloths, surrounding my bed. Each time I wake up, they are no more there."

N: "Does that worry you? Does it mean anything rather than being a dream?"

P: "Don't you think I am going to die? You see these two five cent coins on my locker? (I nodded). This dream started when I put them here. Now I am afraid of using them."

N: "Seeing you associate them with this unpleasant vision, why won't you get rid of them - buy something. Take a decision about these coins."

P: "Well, I shall use them to buy fruits. I see nothing wrong in doing that." (I nodded).

Our strong relationship made nurses at times wonder whether we had not known each other before her admission. On 13 January she told me, "Nurses wonder at our relationship. I tell them you were God sent, as I have nobody to regularly visit me, as you do."

The nurses on the ward soon started to refer to Thalasa as my patient. On the 14th January at 10h10 a Nursing Assistant said, as I entered the ward, "Matron, your patient is not so well. She is so weak and refusing to eat. She is going to be happy to see you and perhaps you can persuade her to eat. She is demanding a blood transfusion!" When I reached the patient's bedside, she looked miserable and when our eyes met, she cried. I wiped her face. She said, "I have nausea, lower abdominal pain and epigastric pain. Thanks for wiping my face. I have been watching the entrance for you. I cannot eat my bean soup and my pawpaw today, it is in the refrigerator. O! cousin, I am missing my children!" She cried again and I wiped her and she held my hand.

N: "Cousin, I shall ask the community sister to bring two of your children. The 14 year old and the 5 year old. I shall give them busfare for their return journey.

T: "O! Cousin, the youngest would have cried if she was left behind. Ask Sister to ask them to bring you a doormat. You know I made that doormat Blairwood Hospital. I wish to give you something made by me, as a way of expressing my love for you."

Sister did return with the children and the doormat on the 18th January and I took them to the ward. Her second son also arrived. She saw us come in, she sat up, laughed so loudly and clapped hands, saying, "Ho! Ho! Here are my children! O! Cousin! O! Cousin!" All other patients sat up and nurses

rushed to section four, where Thalaza slept. When she presented the doormat to me, she ordered everybody to be silent. She said:-

F: "Cousin, I am so happy to present you at least with something made by my own hands, which is like a treasure to me."

M: "Oh Cousin, I am very grateful."

Sister: "Oh Thalaza you have done a good thing. We, also, as nurses at all times wonder and praise matron's concern about you. You are now like children of one mother and one father. God bless you, matron."

N/A: "Thalaza, do you see how God cares for you through matron? But what you have done for matron is very good."

F: "I have been longing for this day - to give my cousin, this present."

Son: "Matron, mama scolded me on Friday evening when I forgot to bring this doormat. She said, it is as good as forgetting her as my mother."

M: "Oh Cousin, I am overwhelmed with joy. Thank you very much."

On the 9th February, she told me about a haunting dream of a "tikoloshe" that strangles her at night. She was reassured on grounds of a Zulu belief that tikoloshe fears electricity. On checking her treatment I realised she had not been given her sebaton. The next day she sent for me at 10h30 and she said:-

F: "I am sure you have been to these meetings! As for these meetings! I am in pain, I did not sleep last night, (she wept) you know this disease is "feasting" on me!"

She shook her head, looked fed up, but quickly collected herself.

N: "Were you not given the injection?"

P: "I was, but I was missing you. I would like to eat grapes and cheese.  
(She smiled.)

N: "Oh Cousin, I shall ask the nurse who is my neighbour who is on  
night duty, to bring the grapes and cheese for you.

P: "You know Cousin, I wish to visit your home, sit on a sofa, enjoy a  
cool drink and then return to hospital."

She then laughed at herself, as if she realised it was just wishful thinking.  
I joined her in her laughter and we held hands.

On the 24th February the Sister persuaded me not to tell Thelma I would not  
be in the next day, as she became difficult. I did, however, tell the patient  
and she accepted it. I asked one clinical instructor and the infection  
control sister to visit her at lunch time on the 25th February. On my return  
on the 26th February, the one Sister reported:-

Sister: "I found your cousin crying when I visited her, but when I  
mentioned that I was sent by you to see her, she immediately smiled  
with those tears. She said you are the only person who cares about  
her. She stretched her arms and told me she was "finished" and  
about to die."

N: "What did you say to that?"

Sister: "I was shocked to hear a patient say that. I think she realised

I got shocked. She then told me she was spiritually ready to die, with the assistance of her cousin."

"I am happy to hear that and thank you for your assistance."

As it became evident the patient was dying, the nurses reported all their problems experienced with the patient, to me and so did the doctor. The patient was identified with me. On the other hand, they pitied the researcher. On the 2nd March, sister informed me:-

Sister: "Your patient is refusing the morphine injection."

Nr: "Is she in pain?"

Sister: "I did not ask, but I can see she is in pain. The doctor saw her this morning and said she is dying."

: "What is your opinion?"

Sister: "I think so, too. Oh! But I pity you. You have cared for her so well."

As the researcher left the ward, the staff nurse and a nursing assistant approached me.

DNr: "Oh! Your cousin is dying. She cannot eat or drink."

NrAt: "Oh! You have cared for her so well."

#### FAMILY SUPPORT TO THE PATIENT

The family had not visited her from the date of admission, that is,

29 December, until the 10th January, when they came back with the community nurses as I had arranged. The aunt came with the three children. She came only three times after that on 22 January, 29 January and then on the 29th February.

The aunt was urged to visit her regularly. She claimed she was a very busy person, but would try to find time to come.

The aunt avoided discussing the dying issue with the patient. She just assured Thalata that her partner was supporting the children.

Thalata's second son came three times during her hospitalisation. He always left her some money and this she appreciated. He phoned twice to enquire about the mother's condition. In his visits he did not discuss the dying issue with the mother.

#### CARE-GIVERS' SUPPORT OF FAMILY

The care-givers who met the family were the nurses and the researcher.

##### Nurses:

The nurses were scared of discussing the condition of the patient with the family. They took it for granted that they could see for themselves she was dying. On the 15th February, the Sister in the ward told me that Thalata's son had visited her on the 14th February. Sister noticed that the patient was withdrawn and irritable and did not talk to her son.

Dr: "Sister, what did you do about that?"

Sister: "Nothing. Her son is old enough to see that the mother is dying."

They were careful in breaking the death news to the son. Sister called him into the duty room, comforted him, and offered a junior nurse to accompany him to the mortuary.

The family were very grateful to the nurses for the care they rendered to Thalaza. They sent messages of praise and thanks through me on the day of the funeral and on the day of the washing of hands ceremony.

#### Researcher:

The pathetic story of a woman, deserted by her husband, having left children alone at home, prompted me to involve the prayer woman on 7 January and the social worker on the 8th January. The community psychiatric Sister was asked to visit her home to check on the children. There was also the problem of the 16 year old daughter who was reported by Thalaza as suffering from blackouts. When we went to Thalaza to get directions to her home, she said:-

"O. Cousin, you have found me good people - the prayer woman, the social worker and now even a person to check on my children!"

N: "Yes, we work as a team."

R: "So, I can rely on the prayer woman, this sister and you."

I had to pop out some money twice to assist the children to come and see their dying mother at the hospital. The children were very happy to see their mother.

The researcher maintained the support of the family after the death of the patient. The son felt I had acted as a mother to the patient. He said; "I hardly saw you, as I often came over weekends; but my mother spoke so well of you. She said she even forgot she was an orphan. You did for her and her children the things that only mothers would do for their children." The brother to the patient said, "We as a family have heard of your assistance to my sister and her children. We thank you for your concern."

On her death I realised that I had seen only very few family members before her death, compared to the number I was introduced to afterwards. I met her partner/"husband" at the mortuary after death. He was very withdrawn, but thanked me for the care of the mother of his children.

#### PATIENT'S FAMILY WORRIES

From the first encounter with Thalaza, she expressed her worry about her dependent children - the three at Mtungini. On her admission she worried most about her 14 year old daughter, who has Blackouts. As soon as I had arranged with the community psychiatric nurse to attend to her children, she sort of settled down. She seemed to worry most when she felt she was dying.

She worried about her partner. She claimed he had deserted her and after the aunt's visit, she expressed hope that her partner would care for the children. It seemed she suspected that her aunt told me how they separated with her partner.

Thalaza worried and was negative about her first son, who works in Johannesburg. She said, "My first son is like his father. He does not write and sends no money - he is useless."

The patient hoped that the aunt would care for the children - but at times she had doubts. For instance on the 6th January as she told me about the family, she cried when she came to the point about her children.

P: "O! Nurse, O! Nurse ---" Paused and cried.

N: "Why are you crying - please tell me."

P: "It is the painful thought about my children."

N: "I understand, but we should be consoled that your aunt is caring for them."

P: "Yes, nurse she does and you also care."

She closed her eyes, put her head on the pillow and forced a smile. She was assisted to a comfortable position. I sensed that she did not want to go any further with the discussion.

On the 20th January when the community psychiatric Sister returned from checking the children for the first time, she was very anxious. Sister reported as follows:-

Sister: "Matron, she saw me going past the window towards the main entrance. Nurses in the ward were startled by her shout, as she said, "There is sister with my radio! O! I am going to hear about my children." As I approached her, she tried to sit up and smiled. I could see her anxiety and I quickly said, your children are alright and were very happy to hear about you and about the food parcels I had taken along for them from the social worker."

P: "That is wonderful sister!" Clamping hands with joy.

Sister: "I examined your daughter and she has not had a fit or blackout since you left."

P: "God is wonderful, sister! I hope cousin shall get me a battery."

On the 10th January, I visited her at 12h30. She seemed to be unhappy and when I questioned her, she ultimately said:

P: "Well, if you are sick, with children left alone at home, one is bound to worry."

She tried to force a smile, as if to conceal something - her sincere deep worry.

On the 15th January, when we discussed plans for the future, when she had verbalised her acceptance of the fact that she was dying - she immediately referred to her children. She also discussed her worries about her children, with her aunt, at her second visit.

Although she was very ill and weak, she expressed her wish to visit home, on the 21st January. On the 19th February, when we prayed together, she could only say, "O! God Help! O! As for my children." She cried right through the prayer. From that day, she never expressed her worries about her children. I did not say anything about them, either.

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

On my third visit on 4 January, I planned with her to contact her people.

When I asked what else I could do for her, she said, "O! Pray for me." On the 7th January, I introduced to her a prayer woman, who was a domestic worker at the hospital. She was happy and stretched out for a hand shake and said: "Thank you for coming, I need your support." This prayer woman visited the patient regularly, until her tragic death, in a car accident on 20 January. I then arranged a nursing assistant to attend to her.

On the 19th February, the patient was very ill and very helpless. She wanted to go home.

P: "O! Cousin, I am so ill, its better to go home. You can see I am finished."

N: "Who is going to assist you at home?"

P: "Well, ---- But I want to go and perform a custom."

N: "Well, I understand about customs. Can you tell me in relation to what?"

P: "O! Cousin! ---- O! Cousin ----" She cried.

N: "Just talk, I am listening and you know I am prepared to help you. Feel free to speak."

P: "You see cousin, there is somebody I want to see, who insulted me. hey! Hey! Cousin ---- (cried) she insulted me! She disgraced me! I want to see her, so that we talk and "pour each other water", to wash hands, to show we have pardoned each other."

N: "Well, cousin, what you are saying is very, very important. It is necessary and good to make peace with your neighbour. We must, however,

be realistic, in whether it is possible to physically get there or not.

We have to get a possible way of solving this issue. It is you who was wronged and it is you who can on this bed now say, "I forgive."

(She nodded). There is another possibility cousin, that the person who you, wronged you, also feels you wronged her. Now God who is everywhere who can hear right now, that you are forgiving. You can forgive and give give your heart to the Lord. The best person to help out in this matter is the pastor."

P: "Cousin, can you find me one? I am so weak! Oh As for my children. Get me a pastor."

N: "Cousin, trust in God - He provides. Just as He provided me for you, (nodded) so in the same manner He will provide that your partner shall continue to care for your children."

P: "Yes, cousin. Yes, cousin, when is the priest coming?"

N: "Oh Let us pray and God shall help me find one."

I dashed back to the office and phoned the various pastors in vain.

It was Friday at 15h30 when I ultimately recalled one of the Medical Technologists, is an ordained Anglican priest. The supervisor allowed him to go along with me. I dashed with him to the ward and introduced him to the patient. I pulled a screen around the bed. We prayed together and Thalata prayed. I was so happy. I met the two clinical instructors as I went out of the ward. I burst out with tears of joy and said to them, "My cousin is with the priest and she prayed today!" One clinical instructor was stunned and the other joyfully said, "God be praised!" Half an hour later the priest returned

For the rest of her hospitalisation she was spiritually happy and would tell me she is praying. When she was gasping, on the 3rd March, the nurses on duty stood around her bed, sang a hymn and prayed, until she died!

#### FAMILY'S REACTION TO DEATH OF THE PATIENT

All the family members reacted in the same manner - they immediately accepted death. It was felt this was so because they had all anticipated her death and had wished that God relieved her from the pain and suffering. The following were verbalised:-

Son: "Well, there is nothing to say, God has taken her. She had suffered a lot of pain. It was as well she died."

Daughter: "She was too ill to survive. I personally lost hope long ago. Since January I have been expecting this sad news. I was not shocked to be told she is late."

#### CARE-GIVERS' REACTION TO DEATH

The Night Superintendent and her deputy, besides pitying me for my patient who had died, said, "I think she rested. She had suffered a lot."

The team of matrons at tea also sympathised with me for the loss of my patient, but reassured me she was too ill to survive and that God relieved her from suffering pains.

The ward caring team (nurses) all crowded around me, when I went to the ward on 4 March and sister said:-

Sister: "Good morning Mrs Mtalane. We are so sorry for you about the death of your cousin. We have all been talking about your concern for her and giving her total patient care. You helped her a lot. In her last days she found a true friend and companion, who even assisted her to meet her Lord."

N: "Thank you. How do you feel about her death?"

Sister: "We all feel that she rested, and was too ill. Each day, seemed difficult an painful to live through."

All the other ten nurses nodded. The senior doctor came in and walked towards us.

N: "How do you feel about your nursing care?"

N/A: "We feel satisfied that we cared for her so well. We even prayed with her, as she gasped to death. We thought of your concern and, that you would have prayed with her, were you present."

N: "Don't you normally pray with the dying patient?"

N/A: "To be honest, we do not often do it."

N: "Thanks a lot."

Doctor: "Your friend died. I told you!" - said that jokingly as he passed.

As I walked out of the ward, I cast my eyes on her bed in section four, in the corner. It was empty, re-made into an admission bed. I felt sore, empty-

handed, my cousin was no more. I felt tears hot in my eyes and I walked out of the ward.

At the mortuary, as I assisted with placing her in the coffin and as I prayed, I cried - and remembered I was a nurse and had to reassure the family and controlled myself. I must admit, it was difficult. I kept on sobbing. Inwardly, I was satisfied I had done my best for her. A cousin I had come to know since the 4th January, was all of a sudden gone.

#### DEATH RITUALS

At the mortuary we prayed together. When the coffin was lifted, the uncle took out from a bag, a ziphuf-mucronaa twig and put it on the floor. He then called her spirit in the traditional way, saying, "Thalasa, my daughter, come along with us, we are now going home. Thalasa, come my child." He then walked in front of the coffin bearers and never turned back. When he reached the barkie and as the coffin was placed onto it, he said, "Thalasa, we are getting into this barkie. We kept quiet until he reached home.

When we reached home, the uncle told the spirit they were getting off the barkie and going into the house. The coffin was taken into the mother's hut - referred to as granny's hut. There was the slaughtered goat meat in this hut. He put the twig on top of the coffin. A prayer was said, before we proceeded to the graveyard. As we left the house, the uncle picked up the twig and said to the spirit, "Thalasa, we are now going to put you in your 'last house' (grave) to rest, where your ancestors are. We hope you shall be a good ancestor and bring us and your children good luck."

When the coffin had been lowered into the grave, a prayer was said and then the uncle spoke to the spirit and ancestors. "Thalaza, we have placed you underground to rest with your forefathers. Our forefathers, meet your daughter and let her be happy with you in your under-world."

The uncle explained to me that it was imperative that we go home first. The reason was to inform the ancestors she had died. He also emphasised she had to be buried in the afternoon as an adult.

On return from the graveyard there were two basins at the gate, one with plain water and the other had water to which was added the goat stomach contents. This was for the washing of hands ceremony. The plain water is for those who do not believe in the washing of hands ceremony. The uncle explained that the washing of hands ceremony, is for washing off the pollution that is brought about by death. The pollution affects the family, the neighbours and those that attend the funeral. He also explained that since the death news was received all the neighbourhood ceased field work out of respect. They would only resume work the following week.

The children were to all have their heads shaved by the aunt and uncle, at the extreme end of the yard. They were to put on a black mourning string around their necks. The adults were to wear a black mourning cloth on their arms.

After the washing of hands, the men went into one hut and we females into another. The goat meat was served with dumplings. As people finished eating they left one by one.

The researcher enquired why they performed the funeral in traditional and christian manner, the elderly aunt, said: "O! Yes, my child. These days, the Zulus are losing self-respect and their dignity by rejecting their customs. People that take up christianity with excitement, lost their culture. Look at the Blacks today, where on earth have you heard of burning a human being alive? The nations that came with Christian religion observe their culture and they are so dignified. If you do not observe your customs, you provoke the anger of ancestors."

The researcher further enquired whether there were any other ceremonies to be performed. The aunt informed the researcher there were two. The second washing of hands, which should be after three months. The other, was the final "buyisa"/return home ceremony after two years. She told me they were to perform the second washing of hands earlier than three months. They were to do it over the Easter week-end, to ensure that all the family is present, as they were working as far as Johannesburg. I told them I will be present and asked for the exact date. They gave me the 4th April, 1988.

I asked them, what had strengthened them during their time of sorrow.

The aunt said, "My child, it was the good spiritual support of our neighbours. They prayed with us, said comforting words, brought food and cool drinks. They remained with us day and night until the day of the funeral."

On the 4th April, 1988 I joined them. A goat was slaughtered in the morning. All the family was to remove the mourning cloths/strings and the aunt burnt them outside the fence, to prevent recurrence pollution. There was a basin with water, to which had been added stomach contents and bile. On this day,

only the family washed hands. I was also asked to wash hands, as I was as good as a family member.

All the people sat on the lawn and a prayer was conducted by the uncle. Men then went into their hut and so did the women. Everybody sat on mats. Meat was served with dumplings.

Before leaving, I enquired about the children.

Aunt: "Their father and his girlfriend are caring for them. Oh My child, that man is good. As it is, after this ceremony the children shall go to their paternal grandmother. She is a very good woman."

Me: "I am happy to hear that."

Uncle: "Nurse, the children are alright as long as they are under the care of their father. He loves them and they are very attached to him. (I smiled). I can see you are happy to hear that. (I nodded). Nurse, before you leave, may I on behalf of the whole family, thank you very much for all you did for the late, her children and us all."

The whole family and the neighbours were by then all standing around me. They all shook my hand, saying thank you. I told them that was my last visit. The brother said, "If only all nurses could be concerned for their patients like this!" All the crowd applauded that remark.

It disturbed my feelings to see the five year old daughter. She so much resented my late cousin. She kept on holding my hand and even accompanied me

to the gate when I left. I inwardly felt she wanted to go with me to the hospital, to probably see the mother, who existed no more.

At the time I attended to Thalaza, early in March, there was a teenager who was critically ill. She would look at me each time I passed, until I attended to her. In fact, Thalaza, had told me she was just like her, very ill and had no visitors. The next day, as I passed she was sweating profusely and asleep. I went to her and mopped her face with a towel. I realised her bed linen was all damp. So, I called a nursing assistant so that we could change her linen and got a fan for her. Her records indicated she had a septic abortion, trauma to urethra and rectal wall. So, she was incontinent of urine and faeces.

She was helpless. She had been a farm labourer and apparently not a hygienically clean person, as her body was covered with dead epithelial cells. The nurses had made a good effort to get her clean, but there were crusts here and there, that needed lubrication and later washing off. So, when I brought fruit for Thalaza, I gave her some and would spend about three minutes or five before seeing Thalaza. Thalaza pointed out one day, "Do you see, she looks brighter as there is somebody who loves her. The nurses are also caring for her in a better way since that day you changed her linen."

In the week of 23 February to 5 March, at the 10h00 visiting hour, I saw visitors at her bedside. I went to greet the patient and her visitors. The patient introduced me as her aunt who visits her and brings her nice things. She introduced her aunt and sister to me. She then cried. I enquired from the visitors whether they had brought her bad news. They informed me that the granny at home had instructed them to return with her, for the performance of

the slaughtering custom for her. They had hired a bakkiad for R120.00 and bought a goat. The nurses were refusing to let her go home, as she was too ill. They were aware she was very ill and the custom was to be performed for two reasons. Firstly, to inform the ancestors she is in hospital, secondly, to ask the ancestors to protect her life, as she is too young to join them and that would help the doctor's good efforts.

Sister was approached and she said the senior doctor/gynaecologist had refused. He was in the operating theatre. I went to him and put the case and explained they were going to return the patient. Doctor asked me, "Do you mean that at the level of your education, you still believe in the ancestors?" I told doctor that I do know the culture of my people and that all the slaughtering custom will do for us as the caregivers, is to boost up her psychological attitude that she is going to make it. I suggested that they sign refusal hospital treatment, so as to protect us, in case they do not return her - which I doubted. The doctor agreed and said she must be back the following Tuesday.

The relatives accepted the arrangement of signing refusal hospital treatment. In the morning of Wednesday, the gynaecologist sent a message through the area supervisor/senior matron, that I be informed that my patient had not returned. On Thursday of the same week she arrived with the aunt and the sister and they were very grateful. The patient was smiling and endlessly telling me how grateful the granny was and that now she can be sent to the operating theatre and will recover. Surely, she was so positive to all the care - the bloodtransfusion, intravenously administered antibiotics, intravenous fluids - which was meant to strengthen her for a major operation and general anaesthetic. She even asked sister why the occupational therapist does not

give her something to do. So, in a few days time I found her doing some wool  
brochet work.

In the third week she went for an operation. She recovered within the  
expected period and then commenced physiotherapy. Both legs were weak and  
could not walk. She is still in the hospital attending physiotherapy. In her  
walking exercises along the passages, she now and again would visit my office,  
to just demonstrate her progress. At times when I visit her and her family has  
been, she shares with me the provision they had brought. At times, the aunt  
would visit my office, to bring greetings from the grandmother, whom I am told  
adores me.

The senior doctor now often calls me to interview patients not responding  
to his treatment - in case they wanted a pass-out to perform the  
slaughtering custom.

## INTRODUCTION

Mr Abram was a 49 year old married man, and a father of seven children. He was hospitalised on the 4th January 1988. He had been known to me since his previous admissions, dating back to 1983. Since he was an important member of the community, I had always to check on him during his hospital stays in my capacity as nurse administrator. He was also a very close friend to my in-laws. He respected me and always called on me if he had any problems, even on personal matters.

## ON ADMISSION

The nurses' notes on the admission interview sheet indicated that he was admitted in a sound mental state. He complained of constipation and a throbbing pain in the chest, radiating to the epigastric region. The pain was aggravated by swallowing. He said that this pain had caused him loss of appetite and loss of weight and caused him sleepless nights.

The doctor's notes indicated that Mr Abram was worried about his illness. The differential diagnoses was pancreatitis and cancer of the oesophagus. The doctor had prescribed a liquid diet and an analgesic.

## FAMILY BACKGROUND

He was a married man and his wife was forty-five years old. He had seven children ranging between 27 years and 2 1/2 years. He was an induna of his clan, and a clerk of the Tribal Authority. He had a huge sugar cane field and a large area for cash crops, from which he had a reasonable income.

He was the key bread winner of an extended family consisting of two grandmothers, two of his father's wives (his mother was deceased), his brothers and sisters, his wife and children. His 27 year old son works in Durban and visits at the end of every month and over long weekends. He assisted in the financial support of the family. The rest of his children were still schooling.

He had an uncle in the vicinity, to whom he was very attached. The uncle had two wives and a lot of children.

The patient was a Christian belonging to the Congregational Church. His educational standard was Junior Certificate. He was a dignified, well mannered, polite person. He spoke English fluently with the doctor and nurses.

#### MY FIRST ENCOUNTER WITH THE PATIENT

This was not actually the first encounter, as already explained. I approached him to seek his permission for the research on the 12th January. He readily consented. He declined to sign the consent as he saw no need therefor. He refused the tape recorder saying it would reveal his identity.

The patient appeared to be depressed. He was very emaciated and unable to stand. He was alert and communicated well. He wore his own decent pyjamas and had his wristwatch and spectacles on. On his locker there were lovely flowers, and six get-well cards. There was a newspaper on top of his bed. He was lying in a propped-up position. On this first visit we discussed his previous and present illness history.

#### ILLNESS HISTORY

##### Previous Illness:

He felt he had been very healthy in his teens and up to the age of 30. In 1965 he developed gastric ulcers. He believed they were caused by taking too much alcohol. He told me that he got better when he reduced the alcohol intake. He was ill again in 1983, and he said he had fallen back to drinking too much again. He then had ulcers and pain in his feet. I could recall that he had peripheral neuritis. He had been re-admitted in 1985 with the same diagnosis.

After discharge in 1985, he came for a few follow-up visits, and then stopped coming as he felt he was cured. In all the previous illness and the present one, his family had persuaded him to go to the witchdoctors. He had refused their advice, as he did not trust them, or the "sangomas". I asked him what the difference was between the sangoma and the witchdoctor. The patient

said, "The role of the sangoma is to tell how things happened and what is to happen. He does not handle any medicines. The witchdoctor treats diseases with herbs and animal products. But once a witchdoctor gives people medicines to kill other people, or murders people to strengthen his medicines, then he is practicing sorcery and is referred to as a witch-"umthakathi" which means "killer".

Present illness:

The patient related this as follows:-

P: "I extracted a tooth last year. I think it left some poison in my gums. This poison spread down to the throat. It then went down the oesophagus and to the epigastric region. It is stagnant there, but radiates pain laterally and backwards, to the vertebral column. It is worse on the left, where it seems to be localised in the loin.

You see, this has been a slow process. O! But this epigastric pain that radiates to the back! It kills me. I become short of breath and I fail even to sit up. It is so painful. It is difficult to eat and particularly, to swallow. Just look at me - how I have lost weight!"

We discussed his treatment and he said:-

P: "Doctor has been here. He said he shall be returning at 14h00. You seem to have good doctors here. He spoke to me with great respect and made me feel accepted."

As we spoke the family came in - the uncle and his cousin.

P: "I was telling the nurse about my illness. This nurse has always shown concern, when I am admitted here."

Uncle: "My son, I hope you told the nurse everything."

P: "Yes, I did. I cannot hide things when I am so sick."

N: "Yes, he has done that. He is being investigated and then treatment shall be commenced.

Uncle: "Well, we have all the confidence in this hospital."

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was informed by the doctor that he had cancer, after the X-ray report came on the 15th of January. The Sister who was present informed me that his response was a simple "Thank you." He had put his head on the pillow and never uttered a word thereafter. Doctor had gone on to tell him he would be sent to King Edward Hospital for further assessment and management. He pointed out the possibility of an operation. To that the patient had said that he would first have to discuss that with his family and his people.

At 13h35 I was called by the Matron supervising the area to come and talk to the distressed and uncommunicating patient. The matron was aware that he was my research case. So, when I came to his bedside, he turned as he was facing the wall, and hastily said:-

P: "O! It is good you have come. Come and sit next to me."

N: "How do you feel today?"

P: "I really do not know how I feel. Doctor has told me I have cancer. You know, my sister, I have always prayed and wished that God takes my life in any way or manner, but not cancer. I have all along maintained a thought, that it is terrible to live, knowing that you are going to die. Death was never meant to be expected as a guest."

As he spoke he was restless, kept on tying and untying his gown belt. His voice became shaky and his eyes glassy, and he kept on sniffing.

N: "Yes, that is correct. But now we know, and you are going to be assisted and you shall be good, and participate in your course of treatment. We shall both discuss your feelings and plan for the future. I can see you are disturbed for now, and you should be. I ....

P: "Yes, I am. Can you phone my wife and uncle to come this evening?"

N: "Yes, I shall do that. Know this, I very much care for you and I am prepared to assist you and prepared to discuss all your feelings." I helped him to be more comfortable with his pillow.

P: "Thank you, my sister. I want to sleep now."

The following week, on the 18th January, he looked a bit more settled after the shock of the diagnosis. He spoke anxiously and slowly, saying:-

P: "Matron, I am really sick. I have been thinking about my illness and recalled a lot of facts."

N: "What are those facts?"

P: "At the age of 30 I was ill. I felt something winding in the stomach. I felt funny and breathless. I went to several doctors, but saw no cure in my condition. You see, medical treatment seems to lull the disease. So I went to a Zulu prayer woman at KwaMashu. She just opened the Bible and asked me to fetch water in a basin. She added some salt and powder into the water. I had to drink this emetic. I vomited a lot of greenish-yellowish stuff.

The prayer woman told me I had been bewitched with grave and ant-hill soil. This soil was meant to grind me inside. What I vomited was a sticky grainy substance of soil. It means this soil did a lot of damage in my oesophagus as well, hence the cancer. Do you remember, when I was admitted with painful, sweating toes and fingers in 1985?"

N: "Yes, I do remember. Doctor explained to you what it was and the cause."

P: "Yes, but that was the Western explanation, when in fact it was bewitchment. What did doctor do? He lulled it, and you see now it is cancer. Is it not a fact that doctors do not know what causes cancer?"

N: "Yes, but ..

P: "It is the works of witchcraft!"

N: "But cancer affects all races."

P: "Yes, but you never know what other races give as the cause, and how they treat it in their traditional way."

N: "Do you imply that you are not going to continue with medical treatment?"

P: "No, I will, my sister."

The patient showed a complete change in direction of thought, in his perception of what caused his illness. Initially he accepted that it was a pathological condition. Once he understood he had an incurable disease, he believed he was bewitched.

Before going to King Edward, he was permitted to go home first. At King Edward, the doctor told him he was to be operated on. He was handed over to the nurses to show him other patients who had undergone a similar operation. The sight of those patients disturbed him. He saw them struggling to breathe, and the nurses spoke negatively about those patients' prognosis. He had returned to the doctor and told him he would return for the operation, but he had no such plans.

He went back to his home and gradually became very ill. He was then taken to his uncle's home (father's younger brother). When he was very ill and suffering severe pain, a family member was sent to the hospital to ask me to get him an analgesic. I approached the doctor, who did prescribe something for him on his treatment card. I told the doctor that I wanted to go to the patient's home and persuade him to come to the hospital. The doctor agreed. This was on the 18th February.

At 14h00 I left the hospital with the messenger and a clerk from the Magistrate's Office, who is the patient's cousin. We were joined by two other government officials. We reached the uncle's home at 14h30. The patient was lying on a mattress under a tree. He was surrounded by a group of elderly men. I went to the old ladies who were sitting outside a rondavel, and sat on a mat with them. They told me he was very ill and pleaded with me to take him back to the hospital.

The patient was then assisted into the main house, and his mattress was carried in by the men. When he had settled I was permitted to enter. Everybody remained outside and I was alone with him except for two old ladies and the uncle.

When I sat down on the mat next to him, he said:-

P: "So you have come to take me along to the hospital, as a responsible nurse?"

N: "Yes, I received the message and I felt I should come to plead with you to return to the hospital."

P: "Well, I have no objection."

He turned to look at his uncle, who nodded. I then asked for a spoon, a plate and water, so as to give him his pain drops. According to custom, I opened it, squeezed one drop onto the palm of my hand, and licked it. They all nodded. I then gave the patient his dose. This custom ensures the patient that one's treatment is safe. The patient boastfully said to his family, "You see, I told you that my nurse is very humane, and a proper Zulu." One of the grannies said, "Yes, my son, we can see you were right. There she has tested the medicine first."

When we finalised the return to hospital, the aunt said:-

Aunt: "He must sleep here today. We shall then, as elders, inform the ancestors he is to go to hospital, so that they accompany him, protect him and bring good luck and success to whatever treatment doctor shall undertake."

N: "I fully understand that custom. We shall be expecting him tomorrow, then."

The next day, on the 19th February, he was in the ward at 12h00. He was very ill. He told me that he had slept well the previous night, after weeks of sleepless nights due to pain. He also said that he wished one of his people could remain with him in the side-ward. The Medical Superintendent approved of that. It was obvious that the patient was afraid of being left alone.

Although the patient had accepted hospitalisation, he sort of wanted to try everything. On the 22nd February, he confided in me:-

P: "Last evening (21 February) my cousin brought me a syringe, and I gave myself an enema. That is confidential, between you and me."

N: "OK, but do not allow yourself to take doctor's and private treatment. Do you really feel constipated?"

P: "No, it is just that it is not good not to pass a stool for more than two days."

N: "If you are not eating, is it possible to pass a stool?"

P: "No, no, no! You are right! I wonder when we Zulus are going to stop this habit."

N: "Well, as we continue to do community health education, there shall be a change realised in health behaviour patterns."

There were times when the patient would sit up in distress and just ponder, talk to himself and shake his head, even in the presence of his family.

On the 4th March, the patient spoke in a manner that made me feel he was accepting that he was dying. His aunt and wife were present. It turned into a group discussion.

Aunt: "O! Nurse, he is very ill."

P: "Yes, you are correct aunt, the disease is just "feasting" on me. One is just dying slowly. One just ponders with anxiety and frustration, as death approaches. I, at times, look at myself (stretching out his arms for us to see, and sort of inspecting them) - is this me, a brave, strong man, who is like this now; with drips hanging like this!"

Aunt: "Yes, my son, you were healthy and strong. You were brilliant at school."

P: "But, my aunt, you know I was always chosen as a class prefect, and always the youngest of all the school prefects."

N: "Those were signs and indications of your present leadership qualities."

The patient laughed aloud, nodding his head in appreciation of the praise.

The patient's condition gradually went down. He appeared distressed and seemed not to have the will to live. On the 8th March, he verbalised his feelings as follows:-

P: "I feel very weak and depressed. I am experiencing less pain though, with the sedation."

N: "What do you think causes the depression?"

P: "I think it is being ill, and knowing my diagnosis. O! Nurse, as for my children."

He cried bitterly. I held him in my arms, wiped his face and comforted him until he fell asleep under sedation. From the 8th March, he demanded that a nurse remained at his bedside, despite the family member who was always there.

On the 11th March, the patient spoke to me in a very relaxed manner. He held my hand and smiled as he spoke.

P: "I am very ill nurse. The only good thing is that I do not feel pain, because I am being sedated. On the other hand, it makes me sleep most of the time, and I cannot talk to my family. It helps me though, not to be worried by all sorts of people, some who are rejoicing that I am dying. It would be better to be with my family, in these last days of my life."

N: "We are controlling visitors. Now, if you say these are your last days, how exactly do you feel about it?"

P: "I feel helpless and as I ponder, all my life seems laid before me. I then know I am going to join my ancestors. O! But the worry about my wife and children, of course, I cannot deny."

N: "I understand. How do you feel physically?"

P: "It seems as if my body systems are giving up their functioning."

From the 12th to 14th March the patient was heavily sedated and I never found him awake. On Tuesday 15th March, I was called from a meeting at 09h00, as the patient urgently wanted to see me. When I got to his bedside, he spoke with excitement.

P: "Hello, Nurse, its a long time since I last saw you!"

N: "Yes, I last talked to you on Friday. Yesterday I was here when your family prayed."

P: "You know, I have been thinking that I was dreaming about my brothers and prayer."

(The clear way in which he talked surprised his wife and aunt. They jumped onto their feet and exclaimed, "He is talking to his nurse!").

N: "I am sure it is because you had been sedated when they prayed."

P: "I see. Now please help me. I cannot sign my cheque. I am shaky. Can you assist me to make a thumb print?"

N: "Yes, let me get the ink pad."

P: "Hey, I am finished! Is this me, signing with a thumb print, as if I am illiterate!"

N: "Well, there are times of illness for each one of us."

P: "Thank you for assisting me. You are a real helper to me. Let me not delay you any further."

The patient's condition continued to decline. He totally refused to co-operate in his care plan. The doctor became annoyed with him, and on 17th March at 07h30 he sent for me and stormed at me with these words:-

"Matron, your patient is refusing to co-operate in his treatment plan. He has no motivation to live. He wanted to know about his diagnosis, now I am struggling alone. He is just passive. So, I have stopped all treatment, yesterday (16 March). Just go and talk to him. I shall not go on treating him, if he behaves like this!"

Doctor spoke with gestures, and it was obvious he wanted no response from me, and walked off. I went to the patient, and found out he could not talk. He was just staring. He never spoke again. He died on the same night, at 01h15 on 18th March 1988.

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

The wife was met on the 13th January. The wife told a similar illness history as the patient. She was worried. She said:-

"Nurse, how can a mentally sound person, having been told he has ulcers, continue to drown himself? Tell me! O! No! No!"

N: "Well, I understand how you feel. You are concerned about your husband, and father of your children, and his actions have annoyed you. It is normal to feel like that. It is good that you have spoken it out. There is, however, something that you probably do not know - that is, alcoholics are sick. They have a weak will power, they crave for liquor, and it sort of becomes compulsive to take liquor. They need professional help and support, and family support."

Wife: "O! Nurse I don't know how happy I could be if he is helped out of this on discharge. How long do you think he will be hospitalised?"

N: "As a nurse, I cannot guess. We shall have to find out from the doctor."

The family was not seen again until the 18th February, when I went to persuade the patient to return to hospital. Then they were positive to him being hospitalised.

As they came to see the patient at the hospital, they realised his condition was deteriorating. They had known of his diagnosis on the 14th January, as informed by the patient. On the 29th February, the aunt, in the presence of the wife, discussed the patient's condition with me, as follows:-

Aunt: "He is very ill, nurse. He seems to be afraid. He seems to be afraid of being left alone, and that is not a good sign."

N: "What does it indicate?"

Aunt: "It means he feels death approaching and is afraid. His other worry is that the Sister who is his cousin, is going on night duty."

N: "She will be on night duty, but in the same ward. On certain days she will relieve the matron, but will come to see him."

Aunt: "That will be fine, then."

On the 2nd March, the wife discussed the fact that the husband was dying. She only spoke to me when the in-laws were not there. This was because of the Zulu respect custom, that she keeps silent when the family elders are discussing an issue. She joins the discussion when called upon to do so. The patient was heavily sedated and asleep. She spoke with anxiety.

Wife: "Nurse, he is getting more ill! Don't you think so?"

N: "He is ill, and ..."

Wife: "Nurse, I think he is losing hope of recovery, but, hey, as for this cancer! I cannot even understand what causes it. O! But, I think it is "idliso" - somebody bewitched him." ("Idliso" is some orally taken medicine, meant to kill a person. It is believed to be added into food or beer by a person intending to bewitch the other).

N: "The exact cause of cancer is being investigated, but doctors are able to manage it - at times, successfully. But now, you and I have a responsibility to support him."

Wife: "Yes, I shall do that. O! But I fear the future - to stand on my own!" (She sobbed).

N: "Yes, you should feel like that. Now do you discuss that with him?"

Wife: "O! No, nurse, I cannot do that! I just cannot show him that I can see he is dying. But his doctor is very kind. He spoke to me and comforted me. He said he shall insert a tube to enable him to eat. At least that is something, rather than to keep him at home where we have no means and knowledge of feeding him."

N: "Yes, the tube can assist him, so that he can be taken off the drip. Well, his doctor is very good."

Wife: "Well, nurse, God willing, he shall recover but ..."

She stopped talking when the visitors came into the side-ward.

The next encounter with the family was on the morning of the 4th March, as stated above, when it became a family group discussion - the patient admitting he was dying, and highlighting his achievements in his past life.

In the afternoon of the same day, the aunt came to my office. She appeared quite anxious, spoke in a low tone, and even whispered at intervals. She had this to discuss:-

Aunt: "Do you see he is dying, day by day? Perhaps as a young person you do not see that. Yesterday, he was actually avoiding eye contact. Do you know what that means?"

N: "I might know it differently. How do you interpret that?"

Aunt: "It is a sign that a person is dying. It is serious." (Whispered that).

N: "Well, we understand it the same way. How do you feel about him dying?"

Aunt: "I am disturbed, particularly about his young wife and children. At least my husband died when all my children were married."

N: "Are you able to support the wife, at this difficult time?"

Aunt: "O! Yes, Nurse - I am assisting her to accept that her husband is going."

N: "Does she accept it?"

Aunt: "She is hurting, but fully aware of what is to happen."

N: "What strengthens you at this difficult time?"

Aunt: "I believe that what happens to us has the blessing of God. His wife has said that too. We part to meet in the next world, where we shall be united with God, angels, and our ancestors. So, we pray with him when we arrive in the morning, and when we leave in the evening."

The aunt seemed to be relieved of the anxiety she came with, by the end of the discussion. She then left for the ward to join the wife, at the patient's bedside.

On the 10th March at 13h10, the wife and aunt were at the bedside. The patient was asleep. The wife asked to speak to me outside the ward. She appeared anxious. She had a changed attitude and expressed that the husband was bewitched and could therefore be treated by a witchdoctor.

Wife: "Nurse, he is very sick and I am worried. His neck cannot straighten up, as if there is something heavy sitting on his shoulders."

N: "What could that be?"

Wife: "It is some evil spirit. You see, he can now sit but it prevents him to straighten his neck."

N: "It is good that he can sit up - that shows he is strong. Now, he cannot straighten his neck because of the subclavian drip and the injection he had. It is going to get better as he gets accustomed to the drip."

Wife: "He does look strong, and can even sit up on his own. What else is doctor intending to do for him?"

N: "He is on this very expensive and nourishing intravenous fluid called hyper-alimentation. It is to build his body and strengthen him for the insertion of the tube in the operating theatre."

Wife: "I see."

N: "Did you have anything in mind?"

Wife: "No, nurse it is just the worry about his condition. One day you think he is very ill, the next day he is better. It seems he needs the performance of a custom to "push him forward."

N: "Can you explain what that custom is all about?"

Wife: "A beast is slaughtered, Zulu beer made, and the elders talk to the ancestors to ask them to assist the sick person to push him to good health, or if they (ancestors) feel he has suffered enough, they pull him to rest and join them in their underground world." (She sobbed).

N: "Do you feel good about that custom even though it may prove unfavourable?"

Wife: "Nurse, I believe if he dies, it will be because God and the ancestors would have deemed it fit. You see, ancestors are near to God and will not do anything against His will. So, they will not protect him. If his time has come, I will accept it."

N: "It is good to positively view adverse aspects of life. Do you want to take him home or can the custom be performed in his absence?"

Wife: "Let us wait and see. Perhaps next week he will be off the drip. Thank you nurse, I am sure I have delayed you."

N: "Not at all. It has been good to assist you in your trouble. I shall always be ready to discuss your feelings."

On the 17th March, and the last day of Mr Abram's life, the wife and aunt seemed to sense that death was imminent. The patient was critically ill, with no response to verbal and/or even painful stimuli. The halting of all treatment by the doctor may also have aggravated their frustration and anxiety. At this late stage of the illness when I thought they had accepted the inevitability of death, they came with a new idea. This idea was verbalised as follows:-

Wife: "Nurse, I am now dumb-founded. There is no improvement. He is just remaining the same. We have a feeling that there is an evil spirit which is sitting on him. Actually, it is the spirit of his very close friend who died. Now I have come with a prayer woman, who is going to wipe him with holy water to remove that evil spirit. Can we wipe him?"

N: "Yes, do wipe/sponge him."

Wife: "Thank you, I now feel happy."

She sobbed, and I assisted her wipe off the tears. The prayer woman and the aunt sponged the patient. When they had finished, I asked the aunt:-

N: "What has actually happened with the performance of this custom?"

Aunt: "This holy water had a herb added, which has the power to expel this spirit of his late friend which was sitting on him."

N: "How did you find out about the late friend's spirit?"

Aunt: "Nurse, when you have a sick member of the family you do not just sit and relax. You go out and hunt for help - go to the sangomas, prayer people, and doctors. So, we heard of this from the sangoma; and it was confirmed by the prayer woman."

N: "As the spirit has been removed, what is going to happen?"

Aunt: "Did'nt you see him smile? You see, we are sure if he dies it will be this cancer as doctor says, and not because of the late friend's spirit. If he dies he will easily join his ancestors and not be burdened and disturbed by the spirit of his late friend, which is unknown to the ancestors of our clan."

N: "Thank you for enlightening me."

The aunt in this family was the main supporter and comforter of the patient and the wife. She maintained the role of the strong one in front of them and seemed to be able to express her feelings only to me.

## PATIENT'S RELATIONSHIP WITH ALL STAFF/CARE GIVERS

The caring team consisted of the doctor, the nurses, and myself.

Doctor:

The patient was attended to by one senior surgeon. The patient was able to communicate directly with the doctor in English.

The doctor kept the patient involved in his care plan. On the 13th January, the patient informed me that the doctor had sent him for a special X-ray. When it came to informing the patient about the diagnosis, the doctor had decided he was the type of patient that could be informed. He mentioned this to me.

Doctor: "This patient has cancer of the oesophagus. I shall inform him when I have examined him under anaesthesia."

N: "Do you think he will take it well?"

Doctor: "He appears and sounds mature enough to accommodate that. In fact, he has been persistently asking me about his diagnosis."

N: "He has also asked me, and I said you shall tell him when the investigations are complete."

## CARE-GIVERS SUPPORT OF FAMILY

Doctor:

The doctor apparently did not often speak to the family members. They, however, felt his support through the patient. On the 2nd March, the wife said, "His doctor is very kind. He spoke to me and comforted me. He said he will insert a tube in him for feeding."

Nurses:

This patient was mainly attended by registered nurses. His care was supervised by the senior matron/chief professional nurse. They tended to avoid discussing the patient's condition with the family. On the 29th February, the family came with a witchdoctor into the side-ward; and there was a dispute. In solving this problem, the Matron and Sister in-charge called in the security guard to escort them out of the ward and hospital.

On the 8th March, when the patient's condition was really going down, the Sister was asked whether she discussed the patient's condition with the family, she said, "We talk and comfort them, telling them to put their trust in God."

N: "Is that meant to encourage them to hope for the patient's recovery?"

Sr: "It is difficult to speak in terms of no recovery. But, also, there is no need to even say that, because he is critically ill, and they can see for themselves."

Researcher:

The established relationship between Mr Abram and myself as a nurse and family friend made it possible for him to verbalise all his feelings and needs. I was able to assist him and his family.

The nurses and their supervisor tended to rely on me for dealings with the family. On the 29th February, the patient did not want to take his liquid diet. They informed me that it was the family's influence because the diet contained milk, which did not agree with the witchdoctor's treatment. The researcher had to discuss and sort this out with the family.

#### PATIENT'S FAMILY WORRIES

The patient was very reserved in expressing his worries. The researcher could only associate this with the Zulu culture that men tend to be reserved about the discussion of problems.

The only time he verbalised his worry about his wife and children was on the 8th March. He informed me that he was feeling weak and depressed. On being asked for the reason, he said, "I think it is the illness, and knowing my diagnosis. O! Nurse, as for my children!" He cried openly. The researcher held him in her arms, comforted him and wiped his tears, until he fell asleep as he had been given his sedation.

#### FAMILY SUPPORT TO PATIENT

The patient seemed to identify himself with his father's brother/uncle, whom in Zulu we refer to as the younger father. When he had decided not to return to King Edward Hospital, in January and when the illness became severe, he went to stay with his uncle.

The aunt was at his bedside daily with the wife from the 20th February, until his death on 18 March. They came to the hospital at 10h30 or earlier and left at 16h00, leaving a male relative with him. On two occasions, the wife and aunt slept on a mattress on the floor in the side-ward.

The Sister, who worked in the ward was a cousin to the patient and served as part of the support system. The neighbours who came to pray for the patient on 26 February were not accepted by the patient. The patient informed me that he had chased them away, as they pretended to be Christians. The reason for such feelings was that they had never bothered to come to see him at his home.

A group of 15 - 20 men came to see the patient, who was their induna, on the 26th February. This proved to be very supportive to the patient. They had come to meet him before going to the Magistrate's Office. I organised that they meet in the Nurses Conference Room. The patient was dressed up in his suit and tie. For a number of days his wife, aunt, and the patient himself expressed their appreciation for this arrangement. The patient felt he had not lost his identity as a leader, and felt the self-esteem.

The patient also had a lot of friends that came to see him, even from as far as Johannesburg. A lot of the hospital staff also came to see him. He was for most of the time positive to his visitors, friends and the family. It was at times, difficult to control the numbers.

## INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

The patient's first expression about his faith, was when he was informed he had cancer. He said, "I have always prayed and wished that God takes my life in any form, but not cancer." These words were expressed in despair and despondency, on 15 January. This led to him being negative about God. On the 2nd March, the supervisor anxiously approached me saying, "I wonder if you can help with two problems. Your patient is very anti-prayer even though he is so ill. Secondly, he is keeping a lot of money."

The researcher, on discussing with the aunt the patient's progress and what strengthens her, asked her:-

N: "Do you think it is important that you pray with him and that he prays?"

Aunt: "We pray with him, but he holds a cold attitude. He should pray and confess his sins, and ask God's pardon for all his wrongs."

N: "Are you going to assist him by getting a pastor?"

Aunt: "I think you can do that for him, but not from his home area."

N: "I shall do that."

I phoned the pastor, who promised to see him on Saturday, 5 March. The pastor phoned me on 5 March, in the evening, and said the patient was very happy. He was to see him again. On Monday, 7 March, although I came when he was drowsy from the sedation, he smiled and said, "O! Thanks for the pastor!"

On the 11th March, when we discussed his feelings about the impending death, he seemed positive:-

N: "What strengthens you at such a time?"

P: "It is my faith in God, that death is a must for everybody, and it comes in turns for us all. Actually, the body dies to rot, but the spirit shall live forever."

N: "Did the pastor's visit help you?"

P: "Very much, I pray freely now."

#### CARE-GIVERS ATTITUDE IN INFORMING PATIENT ABOUT DIAGNOSIS

On the 14th January when the patient was to be informed about the diagnosis, the Sister expressed her feelings as follows:-

Sr: "Can matron be present when he is being told?"

N: "Not necessarily, but it will be good if you attended the doctor."

Sr: "Actually, matron, I am afraid to be present. I think it is a terrible thing for doctor to tell the patient he has cancer, because everybody knows its incurable."

N: "Your patient can speak English to the doctor. He has asked to be told his diagnosis, and don't you think he suspects it?"

Sr: "Yes, he has been asking everybody about his diagnosis. It should not shock him."

N: "I hope you play your role, then?"

Sr: "Yes, of course."

Sister reported back to me the next day. She appeared depressed because the patient reacted negatively to the diagnosis. She never said anything to the patient, when he collapsed on his pillows. The zone matron also was distressed about the patient's negative reaction. She urged me to go and speak to the patient. The supervisor again complained about the patient having been told. Her complaint was arising from the patient's fear of being left alone. She said, "I don't think it is good for him that he was told about his diagnosis."

#### DISCUSSING DYING WITH THE PATIENT

The doctor discussed the impending death with the patient when he explained the diagnosis. The nurses avoided discussing death with the patient. They pushed me to doing it, claiming I have "a special gift" for talking to the terminally ill. The nurses also did not discuss dying with the patient.

The nurses failed to take the opportunities to talk to the patient, e.g. when the patient was depressed. On 8 March the patient expressed fear of being alone and the Sister said he was demanding a special nurse. When encouraged to talk to the patient, she said, "No, how and where could I start?"

In the prayer by the family on 14 March, the Lord was asked to relieve him from the pain and suffering. This was interpreted as an indirect way of discussing the impending death with the patient.

#### FAMILY REACTION TO PATIENT'S DEATH

The Night Superintendent reported to me her observation of the family's reaction as follows, "They said they had expected it and felt he had rested. Even the wife was not hysterical, she was just sobbing."

The family was met at the mortuary, on the 21st March.

Aunt: "O! Nurse, we have been conquered. My son is lying there, smiling, and as if he is going to talk. But I shall never forget all that the doctors, nurses and you did for him. Each time he was admitted, he received good care from this hospital."

N: "We are all sorry about his death."

Uncle: "Yes, my child, he has rested and has relief from pain and suffering .... Nurse, we are grateful for all you did for him, whilst a patient here."

The rest of the family kept on nodding. It was obvious there was immediate death acceptance.

## CARE-GIVERS REACTION TO PATIENT'S DEATH

The Night Superintendent's reaction was that of total acceptance, as she said "Well, I think he has suffered and did not want to live with cancer."

I saw the ward nurse at 07h30 of the same day - the 18th March. I started talking to the staff and ended up with all the ward team surrounding me. They pitied me and accepted his death.

S/N: "We are sorry your patient died, but he was very weak to survive. He did not want to live, despite your constant encouragement."

Sr: "We are really sorry your patient died; but I am sure you also expected his death."

N" "Do you think you did all you could for the patient?" They all said "yes" and nodded as Sister continued to say:-

Sr: "Yes, we did. We have been talking about you, that you seem to have a special way of talking to the critically ill patients. You cheer them up, and they relax and die happily."

N: "Thank you for the kind words."

## DEATH RITUALS PERFORMED

At the mortuary, I observed that the son of the deceased was holding an assegai upside down. When asked about it, the aunt replied:-

Aunt: "He is the first son, and should become the next induna. The assegai has been handed over from generation to generation. When we reach home it shall be placed like that at the head of the coffin. It shall be held like that at the graveside until everything is finished; and until the second washing of hands. It is a sign of respect."

N: "Why is it the men handling the corpse?"

Aunt: "A man of his status is respected even when dead. It is a Zulu custom. Even the fieldwork is going to be halted for three weeks; as a sign of mourning by all his people."

The elderly uncle was carrying the ziphuf-mucronaea twig, and stood silent next to the first son. All the talking was in whispers. The aunt said that the twig was for taking the spirit of the late son home and to his people. As the coffin was picked up, the son and an elderly uncle walked in front, after calling his spirit. The other uncle said the praises of the deceased softly close to the hearse. On reaching home the coffin was to go into the grandfather's rondavel, where the meat and Zulu beer was kept. The twig was to be placed at the head of the coffin. Before being placed, the spirit was to be informed that he had arrived home.

N: "How is the family taking the death?"

Aunt: "O! My child, it is perhaps only those who did not see him in pain who might not accept it, but we as the family and the majority of his community, accept his death. Even the wife realised long ago that he was going to die."

N: "But she has been trying traditional healers to save his life."

Aunt: "O! That is natural for one to try till the end. You know those helpless efforts. You remember the day of the signing of the cheque? (I nodded). At home she opened up to me, cried bitterly and said she had lost all hope."

On the day of the funeral, on the 25th March, at 14h00 a Christian service was conducted by the pastor. The 500 warriors then took over. They wrapped the coffin with the skin of the black ox that had been slaughtered. They carried their shields and sticks (no assegais), holding them below armpit level. They sang the traditional army songs, but softly. They walked with reverence and dignity. They carried the coffin on their shoulders. They took about six steps and squatted, until they reached the graveside.

The women and the wife were pushed to the far back, with the men who were in western attire. The elderly uncle presided at the actual burial. The uncle later informed me that he called on all his forefathers, calling them by their names, to meet their son. When the coffin had been lowered, the first son threw in the first sod.

On asking the aunt why both the Christian service and the traditional were performed, she said, "You see, when one dies, one assumes the spiritual form of existence. The spirit goes to the Lord and the ancestors. So, it is important to fulfill that which satisfied the ancestors, or else they are provoked."

After the funeral the wife went to the river to wash her body. On return, she sat under a bush, far from home, and had her hair shaved off. The children had their hair shaved off outside the fence, the next morning. All the family was to wear black mourning cloth, the wife black attire, and the children the black string around their necks.

On returning home from the graveyard there was plain water, and water to which had been added stomach contents and bile of a goat at the gate, for the washing of hands ceremony. Men and women separated to go into different rondavels, and were served with cold beef and dumplings. As people finished eating, they left one by one. The aunt was approached to find out whether there were further death rituals to be performed. She said the second washing of hands would be in the middle of May.

On the 21st May, I reached the family at 13h50. I was introduced to almost everybody as a good nurse, who cared so much, and who shall not be forgotten by the family. The wife smiled as she saw me walk in and said, "I am pleased to see you. I have been wondering lately whether I did thank you for all you did for us - the care, the concern. I shall never forget you."

N: "Thank you. You did thank us all. but how are you?"

Wife: "I was very upset in the first four weeks, and just could not talk about it. But I have gradually learnt to accept, and can recall the care given and all the events to the day of the funeral. How is his doctor and those good nurses who cared for him?"

N: "They are alright. They send their greetings to the whole family."

The aunt informed me that the children had removed the mourning strings in the morning. They had been burnt by her outside the fence to prevent the recurrence of death. The family had washed their hands with water, to which had been added bile and stomach contents. The hands were washed, she explained, to remove the pollution. The neighbours were cleansed by attending this occasion. Women and men went into different rondavels and were served with cold beef and dumplings.

Before leaving, I asked whether there were still rituals to be performed. The aunt said that they shall slaughter a beast and the wife shall remove the black mourning clothes at the end of the year. I explained that I would not attend, but all the elderly people scolded me, so that I agreed to attend.

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A week later, the aunt who was always at the bedside with the wife, collapsed and died. On enquiring about the cause of her death from the family, I was told that it had seemed she had not accepted the death of the son. She was the sister to his mother. Her sister had died when the deceased was a few months old. She had put him on her breast and brought him up. I was informed she always put up a brave front in the presence of the wife and people. She was always found crying in her bedroom. She simply had a cardiac arrest one afternoon when she was discussing her loss with a close friend.

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#### INTRODUCTION

Mr King X. was a 49 year old married man and a father of two children. He was hospitalised on the 7th January 1988. He was known to me as one of the hospital's domestic staff.

#### ON ADMISSION

The nurse's notes on the admission interview sheet indicated that he was admitted in a sound mental state. He was alert, responsive and well orientated. He complained of a marked weight loss, although he had a good appetite. He also complained of a persistent cough and of feeling weak. He was, however, totally independent.

The doctor's notes indicated the same information ending up with a tentative diagnosis of pneumonia and a differential diagnosis of tuberculosis and cancer of the lungs.

#### FAMILY BACKGROUND

He was separated from his wife, who is the mother of his 24 year old son. This son had been in jail for sometime in a murder case.

Mr King was living with a mistress who is the mother of his eight month old son. They were lodgers in someone's home.

He had no links with his wife or his first son. He spoke negatively of his wife and pitied the son, that he had put himself into trouble. He first referred to the mistress as a wife when he introduced her to me. The following day he informed me that she was his mistress. He confided in me the next day, in her absence, that he had never told

her he had a wife. I reassured him that I would not divulge this to her.

The patient was the first son in his family and, therefore, head of the family. His home was at Amatikulu. His parents were deceased. An unmarried sister, with her six illegitimate children - ranging between 22 and 12 years - lived at home with her lover, who is the father of the children. The family home at Amatikulu was close to the other members of their extended family. The patient was the breadwinner for his little son and mistress. He rarely visited home at Amatikulu, although he considered his sister, mistress and little son as his close family members. The sister met the mistress for the first time when he was admitted. The sister seemed to resent the mistress. Mr King was illiterate and not a Christian. He believed there is the King of the Skies, the Creator, and ancestors who were near him. The ancestors protected and guided him.

#### RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

The patient was approached on the 20th January, to request him to be a research case. The patient readily agreed, but saw no need to sign the consent, as he felt he trusted me as a nurse. He refused the tape recorder, saying he did not want his voice to live after death, like those of drama actors on Radio Zulu.

The patient appeared relaxed and was happy that I was to visit him regularly. He was resting on top of his bedclothes on the bed. The locker was clean and bare.

I had seen the patient twice since the 7th January, on my rounds of visiting the sick staff.

#### ILLNESS HISTORY

##### Previous Illness:

The patient stated he had been healthy until March 1987, when he had developed a persistent cough. He felt the cough may have started in 1986 but he ignored it.

##### Present Illness:

In March 1987 the cough was very severe and he also realised he had lost weight. He felt weak.

He stated that he, as a Zulu man, had to examine his conscience, whether the ancestors were happy or unhappy with him. In so doing, he recalled that he had for a long time not slaughtered anything to please them. He felt guilty and knew the ancestors were angry with him. So, he slaughtered for them but it seemed it was in vain, as the illness persisted. He then went to the witchdoctor who prescribed an emetic for him. He vomited out a piece of flesh, which he referred to as "idliso". The "idliso" is a bewitched piece of meat which causes the illness. An evil person will sometimes trick a person into eating such meat by adding it to the meal. I asked him:-

N: "Please explain this "idliso", does it not get digested?"

P: "Oh! Matron I thought you were mature, but you are as good as a

child as far as these things are concerned. How can it be digested, because it has been treated and prepared by a witch? The witch gets his victim at these parties. You eat it and you feel the effects thereafter. The "idliso" gets implanted in the oesophagus or stomach. Once implanted, it starts working on you, like slow poison. It cannot be treated by western medical means, but by a witchdoctor's emetics."

N: "Now, after it had come out (idliso), then surely you should have healed up?"

P: "Yes, nurse, it should have been so but the damage already done was great. I went from witchdoctor to witchdoctor, all in vain. I got fed up and I thought I should come to the doctor. I tell you, from now on I shall never go to the witchdoctor again." (Patient's fury could be read from his facial expression and tone of his voice).

N: "Why do you have such confidence in the doctor now, as you said he cannot treat the idliso?"

P: "Experience is the best teacher. I got fed up with their self-confidence, which proves a failure at the end of it all. What I have seen with the doctors is that they come, three of them at a time. They discuss my disease and tell me they are still investigating. There is no guessing -- they are reliable."

A young woman walked in, carrying a small baby. The patient introduced her to me as his wife. I greeted her.

P: "I was telling Matron about my illness."

Wife: "O! Nurse, this "idlisio" was very strong. It has been "eating him" up, like slow poison. We are now literally bankrupt due to paying the witchdoctors. I don't want to hear anything about them. We now have full confidence in the doctors."

N: "I am pleased to hear you are both confident about the medical management."

The patient had been admitted by the Sick Parade doctor, when he had voluntarily attended. The patient described his cough as non-productive, although each time he coughed he felt as if something wanted to come out.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was more worried about his loss of body weight than about his diagnosis, as he felt it jeopardized his self image. He said, "O! Matron; to be seen by the public decreasing bit by bit, to a miniature adult, a strong man like myself! But well, it seems I have to live with it, as this "idlisio" has well established itself." (As he spoke he stretched out his arms, examining them and showing them to me).

N: "Well, it does happen that illness causes a marked difference in a person's image; but be assured, we know you and respect you." (Patient nodded and smiled).

The patient was informed by the doctor there was something wrong with

his lungs on the 8th February. As he was in the medical ward, he was informed that he would be transferred to the surgical ward, for the specialist to attend to him. He expressed his worry as follows:-

P: "Now, if I transfer to that ward where doctors operate, how can this be actually done? Look the lungs are in here, in this body chest." (Knocking at his sternum and ribs, shaking his head, facing down = worried).

N: "The best thing to do is that you ask the doctor when he comes here tomorrow morning. That will help us stop guessing." (He nodded).

P: "I think you are right. I was even thinking of refusing to go to that surgical ward. Do you see, I nearly made a blunder?"

N: "Not exactly. You were only going to be expressing your feelings." (He nodded and smiled).

On 9 February at 13h40, I found the patient already in the surgical ward. When asked how he was, he responded in an aggressive manner. He sat up in bed and ventilated his feelings, using gestures, as follows:-

P: "I am ill and now doctor says I must go to King Edward Hospital, what for? What for? He says they will thoroughly look into my chest and urinary system. I wonder what is special about these doctors. They look at me, examine me now and again. Do they think I am a toy? Tell me, mother!"

N: "I understand how you feel. You see, there is also a problem

with your urinary system. At King Edward there are even senior specialists, better machinery for examining you. You said it yourself, that doctors do not want to guess. That is the reason."

P: "I see, I see. (Relaxed on his pillow, nodding and smiling). You have relieved my frustration. OK! I shall go then, but I will have no operation there. I will only have an operation here, in my own hospital, performed by the doctors with whom I work with and be nursed by the nurses that know me - as we work together as a family."

N: "Do you fear being operated in Durban?"

P: "It is not good to be sick away from home. I imagine it is terrible being sick amongst strangers."

N: "You can be assured there will be nothing done against your will."

I later learnt from the sister that doctor had informed him about this diagnosis before I arrived in the morning at 08h30. So, in actual fact, his reaction was to knowing his diagnosis. The Sister explained that the patient shook his head, facing down and kept on chewing his teeth, when he had been told he had cancer. He had kept quiet and never said a word until I arrived at 13h20.

On the 11th February, he informed me he wanted to go home first, to inform his people.

N: "Since you are the head of the family, whom are you going to inform?"

P: "You see, I have to perform the slaughtering custom and formally inform my ancestors."

N: "Are your ancestors not aware you are here?"

P: "They do, but not that I am to be operated upon. You see, an operation is something serious and I must assist the doctor. If they know I am to undergo an operation, they shall protect me and the operation will be a success."

N: "Have you communicated that to the doctor?"

P: "No, I thought that requires a respectable person like you, to present my case to the doctor. At times, these young nurses make fun of such ideas."

N: "Allright, I know about such customs. Your doctor respects patients' opinions, so when he comes, ask him."

P: "No, matron - find the doctor and inform him about my request. You know where to find him."

N: "Alright then, let me go and find him." The doctor was found in the operating theatre.

N: "Doctor, the patient wants to go home first, to ---"

Dr: "To perform the slaughtering custom. Tell him he is only going for assessment and not for an operation. I only wish more nurses would do research, then one would know how one's patients

think and feel."

\*\*\* (The second case study was the same doctor's patient) \*\*\*

It was only on the 12th February at 15h45 that the patient informed me that doctor had told him he had cancer.

P: "Well nurse, I am very ill. Doctor says I have cancer. Hey! ... that is terrible. What about this young boy? He shall grow up not knowing me - his father!

N: "Well, things have turned out like that. Let us discuss this and plan for the future."

P: "What worries me is that his mother is very young and after my death, she will remarry. All men, like myself, do not want a woman who marries with a child. It is better if it is a girl, because then there is hope for the "lobolo"; not a boy who is one day going to be returning to his people."

N: "That is good reasoning. Now, who among your family do you think is responsible enough to take care of him?"

P: "I think my nephew, he is responsible and mature."

N: "That is good, we are getting somewhere. Do you have any insurance policy?"

P: "No, nurse. Were you thinking about his financial support?"

N: "Yes, that is important."

P: "No, I have always been negative to any form of insurance."

N: "According to your file at Staff Office, who is your beneficiary?"

P: "It is my first son. You know, I must get that changed."

N: "I shall ask the Hospital Secretary to come and see you."

P: "I also made a will with the lawyer. You know I have to think that out. We shall discuss that when I return from King Edward Hospital, early next week.

On the 23rd February at 08h30, the patient was back from King Edward. I found him resting on a mattress, under a tree. He was with his mistress, his nephew and his friend - a male hospital worker. The baby was crawling over him, playing with him. The patient was helpless, but trying hard to play with the little boy. I sat on the mattress with them.

P: "Matron, you are like my real mother. (I nodded). We are discussing a serious matter and you have to participate as you have helped a lot in the past. I was suggesting that my nephew goes home and that he and my sister perform the slaughtering custom. As we are talking, the ancestors can hear us. My case is critical and warrants the performance of this custom in my absence."

Friend: "Yes, mama, he is too ill to go home."

N: "Who will do the reporting to the ancestors?"

P: "There is one of my grandfathers in my extended family. My sister and nephew can arrange and organise everyt ing."

On the 29th February, the sister came to me in the office. She had been to see the patient. She presented the problem of the cheque that required to be cashed for the purchase of the goat. The patient was assisted to the bank by Ambulance on the next day, accompanied by two ward nurses. He was also later assisted in changing the beneficiary to be his nephew. The mistress kept quiet and did not participate in the discussion, according to Zulu custom. As an unmarried person, she cannot be involved in ancestral matters. Also, as the patient's nephew and male friend were present, she had to remain silent, as a matter of respect.

As from the 4th March, the patient was refusing to eat, slept facing the wall most of the time and refused any form of nursing care. He became aggressive at times and selected among the nurses who should give him care. A student nurse informed me that the patient's attitude was better when I had been to see him. So, they were watching for me to go and then rushed to render care. I then recalled that on three occasions his light diet was brought to him whilst I was there and I had offered to feed the patient.

On the 14th March at 06h00, the patient informed Sister that he wanted to go home to die. When I arrived at 13h45, he was disorientated and the next morning he was semi-conscious, until his death on the 16th March at 06h00.

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

The patient informed his mistress about his diagnosis on the 11th February. She came into the office crying, saying:-

Mistress: "O! Nurse, what is this that I hear from him? What will become of us? I have been holding back tears as he spoke to me, saying he has this cancer!"

N: "That was good of you not to cry in front of him. How does he feel about it?"

Mistress: "I feel he is broken up. It is just that he is a man and controlling his feelings."

N: "Well, you and I are going to support him."

Mistress: "Yes, we have to do that. Let me go, I left the baby at home."

I sensed that she wanted to go and cry it out.

I met the patient's sister on the 29th February. She felt that the brother should go home and that the slaughtering custom should be performed. She seemed to feel that there was no chance of survival for her brother. She said:-

"You see, the ancestors can assist him to survive or relieve him from this suffering. Our mother was very ill and staying with me at my lover's home. One day she demanded to return home. When we reached home, she instructed that the goat be slaughtered. She died whilst men were skinning it. So, my grandmother smeared her lips with the goat's blood and said: "Here is your food you asked for, for joining your ancestors." You see, my brother needs the assistance of ancestors to survive or let him rest.

The mistress was reported by Sister as being very depressed on the 1st March. The patient's sister also maintained traditional beliefs about the Creator and ancestors. She strongly believed that ancestors have a protecting hand. She even made an example of her travelling alone from home, so emotionally disturbed, but not getting involved in a car accident.

#### PATIENT'S RELATIONSHIP WITH CAREGIVERS/STAFF

##### Doctors:

The patient was very positive and confident in the doctors, from the time of admission. They were reliable, in that they consulted each other about his illness. They involved him in his care programme.

The patient was negative to being referred to King Edward, but when it was explained to him, he understood. It would seem that the Sister who took notes with the doctor did not explain to him. The patient verbalised his trust and confidence in his doctors, when he wanted them (and not King Edward) to operate on him, as they belonged to one "family" at this hospital.

During the last days of his life, when he was aggressive, the doctor pacified him in his limited Zulu vocabulary. He assisted Sister to turn him (as he faced the wall most of the time), examine him and keep on saying, "OK! Baba."

The doctor respected the patient's beliefs and when the family wanted him transferred to a hospital nearer his home, he discussed that with him. Mr King did not want to be transferred to strange nurses and doctors, so the doctor did not authorise his transfer. The patient's mistress also informed me that he was very happy with his doctor.

#### Nurses:

The patient did not verbalise any negative or positive feelings about the nurses in his ward. The day he wanted to get permission to go home to perform a custom, he made his own assumption that as they are young, they would make fun of his request.

When the patient became aggressive during his last days, the nurses still gave him good care and discretely utilised the researcher as the neutraliser.

The patient and I had known each other since 1979. He had, on his appointment, worked in the nursing service division. In 1981 I recommended him for promotion in another section. We both held trust and respect for each other.

The patient continued to maintain that trust and confidence - hence confiding about the mistress, entrusting me with the responsibility to explain to the doctor about going home to perform the custom; his wish to be operated on at his hospital, about his will and altering his beneficiary in his personal file at Staff Office.

The nurses were influenced by the researcher in their attitude to the patient. On the first day the patient's locker was clean. On the second day onwards, his locker was decorated with some kind of fancy paper - both in the medical and surgical wards. On the 22nd January, the staff nurse saw me come into the ward and she dashed and put a chair next to the patient's bed. She quickly tidied up the locker and assisted the patient to fasten his pyjama top.

The doctor saw me as a person who was able to find out about feelings of his patients. When the request by the patient's sister was reported to doctor, re-transfer to a hospital nearer home, he approached me to establish whether this was his wish. So, the researcher became a mediator and co-ordinator between the nurses and the patient and doctor.

#### CAREGIVERS SUPPORT OF FAMILY

##### The Doctors:

The doctor met the patient's sister only once. This was on the day the sister wanted him transferred to a hospital nearer home. She said, "So Nurse, the doctor spoke to me nicely and explained he is very ill to go home." The family otherwise just learnt from the patient that his doctors were good. This was positively accepted by the family, hence a word of thanks sent through me after his death.

##### Nurses:

The nursing staff just reassured the family that the patient would be

alright, although they know he was dying. A third year nursing student was asked:-

N: "How do you communicate with the family?"

Stud/N: "When they come, we reassure them."

N: "What exactly do you say?"

Stud/N: "We say he will be alright."

N: "Do you know his diagnosis and prognosis?"

Stud/N: "Yes, ma'am. Oh! But, what can we say. You know it is difficult to discuss the anticipated outcome. He is the only hope for that woman with his baby. She has lost hope. Even his sister said, the family realises he is going to die."

By the time the student finished talking, I noticed that she had tears in her eyes.

When the Sister was asked what and how she communicated with the relatives, she said:-

Sr: "I think they see the condition for themselves. His sister is old enough to see and perceive that her brother is dying."

N: "Has she said anything that indicates that?"

Sr: "Yes, she said they want to "goduka"/go home with him."

This conversation with sister was on the 14th March and the patient died on the 16th March.

Researcher:

It was evident in all incidents already described that the caregivers and the patient saw the researcher as the person to give them support.

#### PATIENT'S FAMILY WORRIES

The patient worried about the son in jail. He also worried about his eight month old son and the young mother - as already quoted. With the assistance of the researcher the patient satisfactorily planned his future.

Prior to knowledge of his diagnosis, the patient was worried that his ancestors were angry with him. Although the researcher thought this was over, it came to the surface again when he wanted the slaughtering ceremony to be performed, late in February. The patient expressed his gratitude that the custom was to be performed on the 2nd March. He said, "Thank you very much. I gave my sister the money. This afternoon, the slaughtering custom is going to be performed." He smiled and stretched out his hand and I held it. He was drowsy and fell asleep.

The patient was worried about his sister who is not married, who had six children and that he had not married his mistress. He jokingly said:-

P: "My sister is not married, but has six children from one man. They stay at my home. This man has not even paid "lobold"."

N: "Have you paid "lobolo" for your mistress who stays with you?"

P: "No. I was hoping that my sister's lover would pay "lobolo", then I would use the same cattle to "lobolo" my wife. I am just thinking of taking a knob-kierie and demanding "lobolo" from that man who is even staying on my premises. He is not even known by my ancestors! How can my ancestors be happy with me?" (He laughed).

N: "Well, this seems to be a common problem all over. But, I think the brother of your mistress should come with a knob-kierie also and demand the "lobolo"! (We both laughed).

In this case, the patient's worry was that if he dies the sister would be deprived of the land, according to Zulu custom. It is the man who can acquire land for his family, not a woman.

#### FAMILY SUPPORT TO PATIENT

The mistress, the sister, his close friend who was his colleague, his nephew and the researcher formed the family support system. The researcher was included by the patient when the slaughtering custom was discussed. The Zulu culture is very discrete in that it is only the family that gets involved with things pertaining to ancestors.

The mistress paid him constant visits, bringing along the baby. His sister came twice only, but was prepared to support the patient in getting the slaughtering custom performed. His close friend visited him daily in the ward. He also assisted in the discussion for

preparations for the slaughtering custom, as included by the patient. His nephew came twice. He was young, about 22 years and came to check on the uncle on behalf of his mother.

It was this patient's friend and the researcher who mainly supported the patient to discuss his problems. It is supposed the mistress did, although she always maintained her silence in the presence of any other person.

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

The patient's beliefs were traditional. He believed that the ancestors were the key determinators of his fate. He had to perform the slaughtering ceremony to be at peace with them. He believed there was a Creator. The ancestors were like angels to link him with the Creator. If he died, he was to join his ancestors in their underground land of happiness.

#### ATTITUDE OF CAREGIVERS IN INFORMING PATIENT ABOUT HIS DIAGNOSIS

The doctors informed the patient about his diagnosis, as soon as it had been confirmed.

The nurses were all negative about telling the patient his diagnosis. Some of them expressed it as follows:-

Sr: "Well, the doctor in this ward believes in telling patients their diagnosis."

N: "Are you happy with that practice?"

Sr: "I think it is not always good, or rather I should say, it is not good."

N: "Why?"

Dr: "The patient is not taking it well."

Another Sister pointed out that the patient thinks too much about his diagnosis, until he gets disorientated and his condition was rapidly going down, day by day. A similar opinion was expressed by a second year nursing degree student. She felt this particular patient was not suitable. Asked who should be told, she said:-

Stud/N: "Well, I don't know, but this one was not suitable. I pity him."

N: "Why?"

Stud/N: "I think it is not good to know you are going to die."

N: "Have you discussed with the patient how he feels?"

Stud/N: "No, matron, even the Sisters are afraid."

The junior Sister, asked about the progress of the patient, said:-

Sr: "It is not good, since the day he was told his diagnosis. From that day, he is even resenting any form of nursing care. He refuses to eat and even to talk. He is so weak and helpless."

N: "When did doctor tell him?"

Sr: "On the 26th February. He discussed with him his diagnosis and prognosis. You know him, he is a good-hearted surgeon. He let him ask questions. They spent about ten minutes. I don't think he is happy about his condition now. He should be blaming himself.

N: "You mean doctor is aware of the patient's negative reaction?"

Sr: "Yes, matron. At times when he asks how he feels, he simply turns to face the wall. You know when he faces that wall, you can think he is reading something on it"

N: "how does the doctor manage him, at that point?"

Sr: "He simply assists the Sister to turn him, keeps on saying "OK! Baba." You know him, he is very kind."

N: "And you as nurses, how do you manage the patient?"

Sr: "Well, there are nurses he prefers to speak to."

N: "Why and how?"

Sr: "I don't know, but we use them to give him care."

N: "Are any of these nurses he prefers, on duty?"

Sr: "Yes, but she has gone to the operating theatre."

The following day, the Staff Nurse concerned was met and had this to say:

S/N: "He is difficult to nurse. He chases me away at times. I go away and return back to him, as I can see he is very ill."

N: "What does he say, when he chases you off?"

S/N: "He says a lot, like "Are you short of work to do? I don't want to see your face!" "I always feel it is because he is irritable, due to being very ill and knowing he is dying. I think he is justified to feel like that."

On the 14th March, the Sister in-charge expressed her dissatisfaction which could be read from her face and gestures made, as she spoke:-

N: "Sister, how is the patient?"

Sr: "He is disorientated on and off. At times your patient can be furious over nothing."

N: "How do you cope with him?"

Sr: "Oh! We try, but as for this doctor telling him of his diagnosis! They are the cause of all this."

N: "Despite that, I think you are doing your best."

I was positive about the patient being informed about the diagnosis. I assisted the patient to discuss his feelings and planning for the future of his family.

## DISCUSSING DYING WITH THE PATIENT

Doctor:

The doctor, although limited by the language barrier, did inform the patient that he had cancer. The patient understood this to mean that he was in the terminal stage of his life. There was no further discussion about dying at doctor's rounds.

Nurses:

The sister became very emotional (had tears in her eyes) in response to the question of whether she discussed dying with the patient:-

SN: "No, ma'am - it is not easy, but where could I start, and how? But I am really sorry for this man. He has been fit and strong amongst us and now he is nothing. But did you see the young mother of his baby? Oh It is terrible, ma'am."

N: "Yes, it is sad to see one of the staff in this condition. But if you were the Sister who had to break the news to him, how would you handle that?"

SN: "Well, I could have thought of what to do, at that time (shaking her head). But ... to tell the honest truth, Doctor once said I must tell the patient he had cancer. I just told the patient that his disease had become complicated."

N: "How did you feel after saying that?"

SN: "I felt good as I had not hurt the patient."

The Junior Sister was asked whether she discussed dying with the patient; she said:-

Q: "O! No, mama, that is not an easy thing to do. Perhaps it is possible for people who are mature in nursing, like you."

The two senior student nurses, as already quoted, felt it was not easy to discuss dying with the patient. One said "even sister was afraid to do that."

On the 14th March, even when the patient said he wants to "goduka", sister could not discuss dying with the patient, although she understood what the patient indicated.

N: "When the patient wants to "goduka", what do you perceive?"

Sr: "Well, as a Zulu I know that in our culture it means he wants to go and die at home. A slaughtering custom is often done, so that the ancestors meet him. I always explain to the doctor concerned and so far, they respect the patient's wish and would discharge the patient."

#### FAMILY REACTION TO PATIENT'S DEATH

The patient's death had been long accepted and awaited. The sister was willing that the custom be performed to assist him to die and be relieved from suffering and pain. So, when death occurred, it was immediately accepted as a reality.

The elderly uncle, whom I met for the first time at the mortuary, said:-

"If we did not perform the ceremony, my son was going to continue to suffer pain for a long time. We are happy for him."

The patient's sister introduced me as a member of the family. She related to the family the assistance I had given to the brother. The rest of the family accepted that it is as good as being a family member to be so concerned and involved. They expressed their gratitude to the doctor and nurses.

#### CAREGIVERS REACTION TO PATIENT'S DEATH

The doctor and nurses accepted his death as a reality and pitied the researcher.

Sr: "I think he has been relieved from suffering the pain. O! He rested. When I told doctor, he said he expected him to die."

N: "Who was there when he actually died?"

Sr: "It is that staff nurse he always preferred." (Signalled her to come).

S/N: "O! Matron, we are sorry your patient died. When I went to feed him, he was just dying."

N: "Did you resuscitate him?"

S/N: "No, we all expected him to die."

Sr: "Matron, doctors do not want to be called for terminally ill patients. They say we must leave the patient to die peacefully."

N: "Do you support that opinion?"

Gr & S/N: "Yes, yes." (Unanimously and firmly said).

Dr: (passing) "Well, matron, I am sorry for you, but there was nothing else I could do."

I also accepted his death as a reality. He was missed as a person with whom I had established a relationship of trust.

#### DEATH RITUALS PERFORMED

The elderly uncle brought the ziphuf-mucronaea twig to the mortuary, to take his spirit home. Before coming to the hospital, they had slaughtered a goat and made Zulu beer and placed these in the late mother's hut. So, we lifted the coffin from the mortuary into the bakkie. He called him by his clan name and told the spirit they were going home. The old man spoke to the twig as if talking to the late, that they were getting into the bakkie and going home with him to join his ancestors. He then kept quiet.

The sister to the late informed me that when they reached home, the uncle would tell his spirit that they have arrived home and would lead those carrying the coffin into the hut with meat and Zulu beer. The twig would be placed next to the meat. The uncle would say, "You are home now. You can join the ancestors and here is your (the late and ancestors) food. We hope you shall be happy and be helpful to us who are still alive."

The Zionist priest conducted the prayer in the traditional manner. The uncle was called upon by the priest to inform the ancestors that we were proceeding to the graveyard to put him to rest.

The mistress was there with the little boy. The baby remained home as we walked to the graveyard.

When the coffin had been lowered, the uncle spoke to the ancestors. The uncle threw into the grave the first sod. As the men refilled the grave with soil, the women sang hymns.

On return home, two basins were placed at the gate - one with plain water and the other, water to which stomach contents had been added. The sister pulled me by the hand to wash hands with the family. The men and women went into different huts. Cold goat meat was served with dumplings. All the ladies thanked me for the care I had given to the late.

I was then led into the late mother's hut and all the family entered. It must be noted that a stranger does not enter into this hut, regarded as the ancestors' residence. I was also asked to pass a word of thanks to the doctors and nurses that cared for the deceased whilst in hospital. I was further asked to thank the hospital staff for the donation that had been made to the family and to thank the medical superintendent and the hospital secretary for the job he had occupied for the past ten years. As I was present, the uncle would not return to the hospital to express the family's gratitude and I was requested to do so on his behalf.

Prior to departure, I enquired when the next ritual was to be performed. The uncle said:-

Uncle: "First when his son returns from jail he will be met outside the fence, his head shaven, sent to the river to wash, sent to the grave to throw a sod, return and wash his hands with water with stomach contents. You see, I am going to dry some stomach contents and seal these in a bottle. The whole family (including you) shall have the second washing of hands on the 6th May."

N: Thank you, baba (father). Who is going to care for the baby? Are you letting him go with the mother?"

Uncle: "Well, we discussed that as an extended family. There is one of my brothers who never had a son - just two girls. So, once the baby is off the breast, after the second washing of hands ceremony, we shall go and see the mother's father, pay two baasats - one for damages and one for taking away the boy, according to custom. That little boy must grow amongst his own clan and ancestors if he is to be a responsible man. That is very important. Many boys that grow with their mothers' families develop disorganised personalities, because their ancestors become angry."

N: "Thank you all for everything. We did all in our power and I am sure all the ancestors and the deceased are happy. I shall be with you then on the 6th May. I shall pass on all the messages to the hospital."

On the 31st March, the deceased's mistress came to see me at work and this to say:-

Mistress: "Matron, I just felt I must come to thank you for all you did for my son's father."

N: "Thank you. How are you coping with your loss?"

Mistress: "Well, I stay with my parents. My parents were fed up with me since I fell pregnant, but since I told them in February he was dying, they seemed to pardon me. There is something .....

N: "I am listening, just be free and tell me, so that I can assist you."

Mistress: "Mother, those days we were at home for the funeral, the elders spoke to me about them taking the baby, when it is off the breast, after the second washing of hands ceremony."

N: "Who made this estimation of weaning the baby off the breast?"

Mistress: "Well, even now, he is partially off the breast. I told them that."

N: "I see. Now do you feel free to part with your baby?"

Mistress: "Well, that is what I wanted to find out from you, if it is alright."

N: "It is good that you make your own decision. It is your

baby, my child, you know all your commitments and shortcomings."

Mistress: "Well, mama, I agreed to give them the child because right now I have nobody to support me and the baby. My parents do not want this baby. I personally feel it is a burden to me to live with provocation from my parents and I have nobody to care for him, even if I had to find a job. The problems I have gone through have taught me a lesson about a pre-marital baby. Now, I blame myself about not adhering to the radio advertisements regarding family planning."

N: "It is good that you have made self-evaluation. What you have said, makes me feel you are willing to give them the baby. Have you involved your parents in that decision?"

Mistress: "Yes, mama, they are in full agreement. My mother even said they would have at least accommodated it if it were a girl. A Zulu boy at teenage will always leave the people who have brought him up, to find the father. She said he can as well go now."

N: "At least your parents are honest in expressing their feelings. How are you coping with the fact that he is gone as your partner?"

Mistress: "Oh! Nurse, I feel empty-handed, but I felt like this since I knew he had cancer, in February. I just lived an empty life. I started to accept it day by day with every

visit I made at the hospital. This acceptance went on up to a final finish of reality, the day he was buried."

N: "That is life my child, and it comes with its ups and downs. Adjustment is the only solution as you have said. And how is the baby?"

Mistress: "He is fine, mama. Let me go and not further delay you."

N: "Thank you, but let me take you to the social worker, so that you can get some assistance."

On the 6th May at noon, when I arrived the uncle led me to wash hands with water with stomach contents and bile. He told me the childrer had the mourning strings removed and burnt outside the fence by the old aunt, to prevent recurrence pollution. The family only, washed hands. The rest of the neighbours who supported them got cleaned from the pollution by their presence.

The women were all in one hut and the men sat in the shade next to the cattle-wraal. Cold goat meat and dumplings were served to everybody. Before eating, the Zionist pastor conducted the prayer in the traditional manner. The people left one by one, as they finished eating.

The uncle was asked whether there were any further rituals to be performed. He told me that the deceased's eldest son was not yet back, so he would preserve some stomach contents again and the son would have to wash his hands twice, when he arrived. At the end of the year, they were to slaughter again and perform the last ritual.

I thanked them all for their co-operation in answering all my numerous questions. They wished me all the luck and felt it would be wonderful if all nurses were like me.

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The close friend and colleague of the deceased came to me two months after his death, to tell me of his dream. His late friend asked him to get his parcel from another male hospital worker and to greet mama. He understood that I was the mama referred to. He had told this other hospital worker of his dream and he had readily said, "Yes, Mr King X had given me his family assegai to sharpen and polish. I had finished that when he was hospitalised, then he died and I have been wondering whom to give it to." The friend told me it was with him and was to get it sent to his family.

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The doctor in the medical ward sent for me, in February, when Mr King had been transferred to the surgical ward, to take up a 36 year old lady who was said to be dying from bronchitis and pneumonia. She was critically ill. The patient was approached and consented to being interviewed for research purposes. She refused to sign the consent as she said she trusted the nurse. She refused the tape recorder, as it would reveal her identity.

She explained her illness as being caused by "idliso" and that she was also haunted by evil spirits that throttle her, causing these severe

bronchial spasms. She knew of a person who hated her and bewitched her. She had been in and out of hospital and to various witchdoctors for treatment. She had been referred to the hospital by a private doctor.

She informed me that she was awaiting the completion of the course of the very expensive antibiotics that were being administered intravenously. The doctor had explained that to her and she had accepted that. To me, this patient's progress was promising. On a Friday I attended a number of meetings and did not find time to see the patient. On Saturday, I probed the ward, only to be told by Sister that the patient had dramatically improved.

On a Monday, the patient was found sitting on a bench, happily chatting to her husband. The husband informed me that he had been to an *leangoma*, who said the ancestors were angry that they have not slaughtered for them for a long time, yet they had blessed them with six children. The children ranged between the ages of 22 and six years. He believed in that, as the wife often became suddenly ill and would be called from work and told she was dying, and then would suddenly recover. He said, the ancestors know when and how to punish their naughty children. They knew he dearly loved his beautiful wife and they knew when she was ill, he would act. The doctor had told him to meet his wife the next day. He thanked me for my concern and care for his wife. When they left the next day, they came to the office to say good-bye.

She was advised to attend the chronic ill clinic at Nseleni Clinic, so that she could be checked by the doctor every three months. I phone her once every month and she tells me of her good progress.

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A Sister in the gynaecological ward informed me of a very ill patient who needed my care. The patient was a 56 year old lady who was transferred in from Manguzi Hospital. She looked at me very suspiciously as I greeted and sat next to her. She relaxed when I introduced myself and explained the purpose of my visit. I requested to use a tape recorder, but she refused. She felt her voice would be identified by nurses who knew her.

I noticed that the patient had a pattern of traditional marks on her face which is similar to that of the Thonga tribe. She spoke with a typical Thonga accent, so that it required me to ask her further questions to ensure I understood her well. This seemed to amuse her and she would speak with gesture. Her legs had marked oedema, she had an itchy rash on her arms, and kept on scratching herself. She had an offensive smell. She explained she had been ill for two years at home and treated by the witchdoctor. The illness was caused by bewitchment. She had a fertile plot and was diligent in ploughing. The jealous neighbours then sprinkled "muthi" which she walked over when she was weeding. The illness then went in through her feet, up to her back causing backache and later developed into lower abdominal pain. It was at that point that she developed oedema of the legs. As she was weeding the "muthi" affected her hands and arms, hence the itchiness. She, however, held no grudges against her neighbours.

On asking her about her present illness, she told me the doctor had told her she had cancer of the cervix. She understood cancer was incurable and that a medical doctor cannot treat a Thonga disease. She accepted that she was going to die and had no regrets as her children were grown up - all married and had seen her grandchildren. She only longed to return to Manguzi Hospital to be sure she would be buried where her ancestors were also buried. The departmental policy of how corpses are returned to the hospitals that had referred the patients was explained and she was very delighted.

I asked her how she felt about dying. She said it was fearful in the sense that she did not know how it felt like and what would come next. She, however, believed she would join her ancestors in the underground world. I asked if she believed in God and she said she believes in the Creator, the "Mvelingqangi" who created us all. She told me ancestors are like angels. She looked tired and I suggested we would meet the next day. She said "Even if you do not find me alive, but you have really blessed my soul by telling me that my body will be sent to Manguzi".

The next day when I went to see her, I only found a vacant bed and was told she died quietly during the night.

## CASE NO. 4 : MRS SIBONGILE X.

## INTRODUCTION

Sibongile was a 36 year old married woman and a mother of three children, aged 15, 13 and 9 years. She was hospitalised on the 15th January 1988.

## ON ADMISSION

The nurse's notes on the admission interview form indicated that she was admitted in a depressed mood, was responsive, and well orientated. She was very emaciated, and complained of severe abdominal pain, dysuria, and dripping incontinence. She was totally dependant. She had been to a prayer woman and had been treated with holy water.

The doctor's notes indicated the same information, and she was diagnosed as having cancer of the cervix.

## FAMILY BACKGROUND

Her close family consisted of her husband, her children, and her husband's elderly aunt. The neighbours were her husband's uncles (younger fathers) and their families. Her husband worked at the Richard's Bay complex, and returned home every afternoon. Her husband's parents and grandparents had died. She spoke positively of all her in-laws.

Sibongile's home was in the same locality as that of her in-laws, at KwaMthethwa, near KwaMbonambi. Her father had three wives. Her own mother was deceased. The second mother was alive, and the third

mother had quarrelled with her father and had left home.

She had been working at Empangeni as a domestic worker. Her brother was employed at Checkers at Empangeni. Sibongile seemed happy to speak of her family. Sibongile and her families were Zionists. She had passed her standard six.

#### RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

This was on the 22nd January, at 06h15. She had had a bath and was lying on top of the bedclothes as it was hot. She acceded to my request to be interviewed for research purposes. She saw no need to sign the consent, as if it is a criminal investigation. She refused the tape recorder as she felt it would identify her. She also associated the tape recorder with a police device.

Her locker was clean and had fruit and orange juice. She was a well mannered, soft-spoken person. She appeared shy, when we started our discussion, but soon relaxed and spoke freely. She pointed out she knew my father-in-law, and felt she could recognise my husband as she understood his sons to bear the same resemblance. She claimed I was a "makoti" (bride) to her, then. We both laughed. She told me my father-in-law was very helpful to the community, and it was good the son had married a nurse, to nurse the KwaZulu people. She felt her family would be happy to meet me. She was reassured that they would.

(In Zulu culture young men at an "isigodi"/locality call themselves

brothers. Families in an "isigodi" see themselves as an extended family. So, when one gets married to a family in an "isigodi", one gets accepted as a bride to the whole "isigodi").

#### ILLNESS HISTORY

She stated that she had been well before June, 1987; except for irregular menses. In June 1987 she developed severe lower abdominal pain. She went to see white private doctors at Empangeni. She was treated with injections and tablets. In between seeing private doctors, she went to various prayer women. All this was in vain there was no improvement.

The two families discussed her illness and resolved that she be sent to the witchdoctor. She went to four different witchdoctors. The illness persisted. She was taken back to three different white private doctors at Empangeni. For each consultation she had an injection and tablets. A family friend recommended a Black medical doctor at the township in November 1987. She was prepared to try anything, so she visited this doctor. She was referred to the hospital, and she came.

On admission, she was examined and doctor informed her that her illness had to be treated at King Edward Hospital. She requested to go home first.

N: "Tell me, was it just to tell them, or was there another reason?"

P: (She faced down). "I don't know whether you know Zulu customs?"

N: "Of course I do, Sibongile."

P: "You see, as a married woman I have to report within the family that I am going for treatment. The family elders, my husband and the ancestors can all be provoked if I do not show respect. They have all to know, so as to wish me good luck, and that doctors' treatment be effective."

Sibongile stayed at home for a few weeks as the slaughtering ceremony had to be performed. She developed painful feet at home and could not walk. A vehicle was hired to bring her to the hospital in mid-December. The following day, she left for King Edward. She had radiotherapy for a week, and was discharged home for Christmas. She came for admission again on 15 January 1988.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was informed about her diagnosis on admission in November 1987. On the 24th February I discussed her diagnosis:

N: "Did doctor tell you about your diagnosis?"

P: "Yes, he said I have cancer of the uterus." (Her attitude and facial expression was so placid and blank, that it was difficult to sense how she felt).

N: "Were you happy doctor informed you?"

P: "Yes, he relieved me of the anxiety I had."

N: "Sibongile, what do you understand about cancer?"

P: "I don't know much, but my aunt was very ill with cancer. She had a very offensive odour and was treated by the witchdoctor, with enemata and blood tonics made from herbs. She was better after that."

N: "Have you sought treatment from that witchdoctor?"

P: "No, I trust the doctor, and I have put my trust in God."

N: "So you hope to be better with treatment?"

P: "O! Yes, because doctor has many more ways of treating disease than the witchdoctor."

N: "Now doctor has said, according to your husband, that he cannot cure your disease, but this witchdoctor cured your aunt."

P: "What cure? My aunt died later." (said with fury).

N: "Well, that is what I understood you to say."

P: "In actual fact I should say she was better for a short while. You see, I also like the hospital because the doctors and nurses do not frown at me, because of my offensive smell."

Sibongle talked about her bodily changes - the inability to retain feeds, nausea, vomiting. On the 29th January, she said, "O! Nurse, my leg is very painful. Look at me, I am so thin, so thin ..... O! the pain." She stretched out her arms to show me. I assisted her, held her arms and rubbed her, confirmed the arms were thin, but that it was due to illness. Sister was asked whether there was any ointment prescribed for massaging her legs and arms. Sister informed me that

the messenger had gone to collect it from the dispensary.

The patient at times described the pain as a "killer" that hits repeatedly until a person dies. She then refused food or a drip, since on days she said we were keeping her alive so that the pain could keep on. So, when I asked:-

M: "Sibongile, besides this lower abdominal and leg pain, is there something else worrying you?"

R: "O! Nurse, to tell you the honest fact, there is nothing alright with me."

M: "I understand why you feel like that. With massaging and tablets for pain, you will feel better."

R: "I am not hoping for anything, I only hope my family visits me today."

On the 3rd February, I found her crying at 13h10, and she said:-

R: "It is the pain and nausea. I can't stand this!"

(On her locker there was a large covered receiver, and half-full with vomitus. I emptied, cleaned and returned it).

M: "You see, we can feed you per intravenous drip, and give you a strong injection for pain. Let me find Sister." (She nodded).

N: "Sister, how is Sibongile's progress?"

S: "She is in pain and vomiting. She refuses the drip. Doctor has

been asked to review the dose of morphine, but he is in the operating theatre. He is coming at 14h00."

N: "Sister, let us go to her so that you tell her that doctor is coming."

Sr: "Sibongile, I think it is good that you accept the drip. Doctor is coming at 14h00."

F: "Yes, you can put it up."

Sr: "Matron, please do not go until I have put up the drip." (I did wait).

N: "Sibongile, I will come back at 14h00, to meet the doctor."

F: "Do come, because doctor keeps his word like you. I trust him."

N: "I am happy to hear that."

I returned to the ward at 14h05. Doctor had seen her and ordered her 20mg Morphine. Doctor stressed to me that she was in the terminal stage of cancer and was very aggressive at times. This, doctor felt, was a normal reaction, but on the whole he felt she had taken it bravely. Doctor brushed her head with his hand and said, "You are a good girl! I have prescribed for you a strong injection. Matron shall explain to you." Sibongile smiled and when doctor had gone, she said, "You see, my doctor, I told you!"

Sibongile sort of made an assumption that all the patients in Section 4 were terminally ill. She expressed her fears, saying

"Unfortunately, we are here far from the nurses' station, and we are so ill. I have no strength even to shout for a nurse." I suggested to sister that she be shifted to section one, as she needed constant attention. Sister did shift her to section one.

On the 2nd March, Sibongile told me of her severe pain, pointing in the right iliac fossa, pulling my hand to feel. I did palpate the area. She also asked me to feel the groin. She seemed happy as I felt with my hand, and expressed herself:-

P: "I have severe pain here. There is just a painful lump. I think it is the kidney."

N: "I can feel it is a bit hard, but it is not the kidney, as the kidneys are up here in the back." (Showed her the position and she laughed!)

P: "Well, thank you. I have always thought that the kidneys are down here, near the urinary bladder, as we hear they eliminate urine."

N: "Yes, they do, but there are tubes that drain the urine down to the urinary bladder."

P: (Sudden changed mood and topic) "You know nurse, I am missing my children. Do you think doctor can allow me to go home?"

N: "What for Sibongile? Why are you crying?"

P: "Do you think I know! It is just a silly wish!"

N: "If you were to visit home, who would care for you?"

P: "My aunt. O! Just to see my children!"

N: "Who cares for them?"

P: "My aunt, and she truly loves them."

N: "But then what is worrying you?"

P: "I miss being with them at home - you know the togetherness of the family."

N: "So, that is what you are worrying about."

P: "Yes, when I see myself bones and skin, smelling offensively, so weak, vomiting on and off - I feel there is nothing left of me. I cannot live forever on a drip, that is what makes me feel I am dying."

N: "Do you fear that?"

P: "Yes; and I want to go home."

N: "Do you discuss your feelings with your family and nurses?"

P: "No, I don't want to upset my family and the nurses that care for me so well."

On Monday 7 March the patient expressed being better because she had not vomited over the weekend. She was happy the sedation kept her free from pain, but at the same time expressed her concern about being drowsy and helpless. She was happy her husband had come with the children.

On the 3rd March, Sibongile was very ill, vomiting, and she was in pain, at 13h00. On checking her file, she had not been sedated. Sister confessed she remembered when she saw me walk into the ward. The next day, Sibongile was very ill and said:-

P: "Nurse, doctor should cut here, (pointing to the right iliac fossa) and take out the uterus! I think that would stop all this pain I am suffering."

N: "Alright, let us discuss this steadily. You always tell me you are helpless. (She nodded). Will you be able to stand the strain of the operation and general anaesthetic and the painful operation site?"

P: "O! No, no, nurse, I can't, I can't. I see it was just wishful thinking and confusion of my mind which is sick."

N: "Do you think your mind is sick?"

P: "Yes, it is bound to be sick, when one is facing a dark future. It is better when somebody who cares like you is around. When you go, all the thoughts about my husband, my children come flooding my mind, and it sort of drowns me in loneliness - and my friend, I tell you, a painful loneliness!"

N: "Do you feel like that both day and night?"

P: "It is worse at night."

N: "I shall find somebody to keep you company during the night."

P: "I shall be happy, my friend."

Sister was approached to arrange that somebody keeps her company whilst awake both day and night - a nurse or another patient who is ambulant. Thereafter, Sibongile reported happily that various nurses and other patients visit her.

On the same day, Sibongile was visited by her younger mother (father's third wife) to whom she expressed that she was "finished" as she had no strength, no hope of surviving, and was praying that God takes her soul and be relieved from pain and suffering.

On the 11th March, it was windy, and cold, but I found the window next to her wide open. She told me she had opened it, because she had a very offensive discharge. It was explained to her that the smell was due to the condition she suffered from.

On the 18th March, onwards, Sibongile was disorientated and her condition deteriorating. She had attacks of nausea and vomiting, and diarrhoea, on and off, until her death on 5 April 1983.

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

The husband was met on 19 January. He was escorted to the office by the ward nurse, because Sibongile had told him he had to see me. He informed me that Sibongile spoke well of me, and reported I visited her regularly. He was very grateful. He told me a similar illness history as Sibongile. Sibongile spoke well of doctors and nurses at King Edward and Ngwelezana Hospitals. He said he tried his best to visit her weekly and they discussed her illness. He was asked whether

he knew his wife's diagnosis.

H: "Doctor told her she has cancer."

N: "Do you know what it is?"

H: "Yes, it is a terrible, incurable disease. I don't know what has befallen my family! It is like a dark cloud; but as a man I have to control the pain I am suffering, and try to cheer her up."

H: "Do I understand you well - you avoid discussing her condition, and just reassure her?"

: "We discuss the misfortune that has befallen us, and try not to appear miserable about it. I reassure her when she tells me about how she feels - the pain, nausea, vomiting.

On the 1st March, the husband was seen together with Sibongile's brother. They told me the children were well cared for by the aunt, except that they were missing the mother. They added, "O! Nurse, Sibongile looks terrible."

H: "Yes, she is very ill. Did you discuss that with her?"

: "No, that is not done in the Zulu culture. We would be finishing her up, if we did. We discuss about her condition alone at home. You know she tends not to look at us, and that is typical of a person who is going to die. We feel terrible."

H: "What do you tell the children?"

Bro: "We just pass her greeting and tell them she is ill. Perhaps they can read from our facial expression that things are bad."

N: "Do you think they are mature enough to do that?"

B: "The older ones I think."

On the 6th March, her third mother, who had separated with Sibongile's father, came to see her. She had seen the brother who works at Checkers, who told her Sibongile was dying from cancer. She said:

M: "Her aunt died of cancer, her mother died of cancer, now it is her. No, this is not good! You know her mother had also a funny growth on her vulva, like a pineapple, and had an offensive vaginal discharge. She is just smelling offensively like her mother, just before she died. There is somebody bewitching this family."

N: "Do you feel she is dying?"

M: "Yes, even the brother told me so. He said they are just waiting for the day of her death - she is as good as dead."

N: "Did you discuss with her about her condition?"

M: "No, but she told me that she is "finished" - no strength, no hope of survival, except that God takes her soul and be relieved from pain and suffering. Tell me, nurse, why does the doctor not remove the uterus?"

N: "I shall discuss that with her, but do you think she is strong enough to stand the strain of the operation?"

M: "I think she is too ill to undergo an operation."

N: "Did you point that out to her?"

M: "No, nurse, that would have discouraged her."

N: "I hope you shall regularly visit her."

M: "Yes, nurse, I shall do that. I am very fond of Sibongile. She used to assist me by caring for my first born. She stayed with me in my hut all the time. She grew up to be a very responsible and polite person."

N: "I am very pleased to hear about that."

On the 18th March I met the husband again. Sibongile was very ill and disorientated on and off. He walked into my office, at 15h00 and just said:-

H: "Nurse, there is nothing left of her. She seems to be in severe pain."

N: "Yes, she is very ill. We are, however, controlling her pain with a strong injection."

H: "She told me, and thank you for your concern. She was such a good wife, I shall always remember her."

N: "I am happy she is a good wife. Her mother also said she is a good person. How are the children and aunt?"

H: "Nurse, they are alright. It is just that we are all tense and waiting for the day (she will die). O! She is suffering! Good-bye nurse."

The family seemed to have accepted that Sibongile was going to die. The brother, at the mortuary on the 12th April, said:-

Bro: "Her condition could not have improved, nurse, due to our big brother's wife's refusal to make a confession together with Sibongile. Do you remember when we performed the slaughtering ceremony?"

N: "Yes, I do."

Bro: "You see, Sibongile quarrelled with her late mother. In that quarrel "makoti" (sister-in-law/bride) was involved. So, Sibongile knew something, which we all did not know, which she and "makoti" had to confess. So, although Sibongile confessed her part, but we feel it was not successful because "makoti" did not participate. She actually ran away from home, on the day of the confession. So, the ancestors remained angry."

H: "Yes, nurse, it is like that. Angry ancestors do not protect life, they take it away. But I pity that "makoti" because Sibongile is going to be an angry ancestor against her, unless she returns home to make this confession before the congregation."

N: "It would be a good thing if her husband finds her and makes this good, and then all of us can be happy."

#### PATIENT'S RELATIONSHIP WITH ALL CAREGIVERS

Doctors:

The patient all the time expressed her appreciation, trust and

confidence, and gratitude about the doctors, at King Edward and Ngwelezana. They talked to her, listened to her problems and did something about them. The doctors on the other hand, understood her aggressive reaction to her diagnosis, and pacified her and the nurses.

Nurses:

The patient told the researcher, nurses were good to her. She said the same thing to the family. It seemed though, they lacked the tact of handling her when she was aggressive. This was expressed by sister on the 3rd February, when she requested me to wait until she had put up the drip.

Oibongile was aware of her offensive odour, and seemed relieved to see that the nurses did not frown at her. This made her positive to hospitalisation.

On the 29th February, she was asked:

N: "Are the nurses doing all you expect them to do for you?"

R: "If I tell you, won't they ill-treat me?"

N: "No. I know how to go about helping you and them."

R: "Well, the day nurses are alright. The night nurses at times disappear and there is nobody to speak to. There are those that come here when my nurses are off - they are terrible. They do not know us, and they do not care about us. Unfortunately, we are here in Section four, far from their office, and we are so ill. I have no strength, even to shout for a nurse."

The next day, 1 March, Sibongile reported positively about the nurses. The patient made her own perception, that nurses knew about her dying feelings although they did not discuss her condition with her. She said, "Nurses, I think, can see what is happening and are caring for me very well."

Sibongile reported positively about nurses when I had discussed with sister, that somebody keeps her company. She said, "There was a nurse who kept checking on me. She then sat here next to me until I fell asleep."

On 18 March, I found the patient kneeling on the bed. There were faeces all over the bed. Two student nurses, who were a month and a half experienced in nursing, were watching the patient struggling to wipe herself. One of them had a basin in her hands and the other a piece of toilet paper and a toilet roll. The patient was mumbling to herself. The two students looked terrified. I came to their rescue. I assisted them clean up the patient. I then called them away from the patient, to ask a few questions.

I: "Do you know what is wrong with this patient?"

Stud/N: "She has cancer of the cervix."

N: "Who told you?"

Stud/N: "It is sister, and she said the patient is dying."

N: "How do you think we should nurse a dying patient?"

Stud/N: "I think she needs to be fed, and that we pray with her."

Stud/N: "I think she needs her family to be near her."

N: "If the family cannot afford to come daily?"

Stud/N: "Sister must allow the family member to sleep here next to the patient."

N: "Why should the family be near her?"

Stud/N: "To keep her company. She should be afraid! Is it not so, matron?"

N: "Well, I imagine so."

I then went to speak to sister.

N: "Sister, how is Sibongile?"

S: "Well, she is dying slowly. There is no hope, but poor thing, she co-operates with us, as we change her linen she tries to turn, and slowly takes her feeds. She is disorientated most of the time."

On the 23rd March, Sibongile informed me that the doctors and nurses were good to her. She said she hoped to go (die) peacefully and happy.

#### CARE-GIVERS SUPPORT OF FAMILY

Doctors:

They never met, but the family developed a positive attitude towards doctors from what they heard from Sibongile.

## Nurses:

The nurses seemed afraid to discuss anything about the patient's condition. On 2 March, when the husband expressed his fears about the dying wife, asked him:-

N: "Do you discuss your fears with nurses?"

H: "No, I think they pity me or are afraid to talk about it, and I also do not want to burden them, as they are doing a good job of caring for her."

On the 15th March, sister was asked how she assisted the family:-

S/N: "One just greets them and says she is very ill, as they can see she is dying."

N: "Staff nurse, how do you assist her family?"

S/N: "They look very depressed, I am even afraid to talk to them. I just greet them."

N/A: "I am afraid to talk to them. I simply offer them seats, if I happen to be here, and pretend to be busy and walk away fast."

## Researcher:

The family informed the researcher about the traditional customs that they had performed, and they were not disputed. This tended to make them have more confidence in me. The husband taught me some aspects of our culture - we do not speak about death with the patient, when a very ill person avoids your eyes it means she/he is approaching death.

Later in the conversation he let go and cried. We prayed together and he left saying, "O! Nurse, you are one of us and you are sharing all with us. So, we trust that when you are here it is as good as us being here." This was re-affirmed by me and he left relaxed.

All in all the family members met were the husband, mother, and the two brothers. The children came on Saturday when I was off duty. Greetings from the aunt and the children were relayed through Sibongile and the husband.

#### PATIENT'S FAMILY WORRIES

The patient was interviewed from the 15th January, but she only expressed her worry about her children on 2nd March. It was in the midst of a conversation about the painful kidneys, she just abruptly said, "You know nurse, I am missing my children. Do you think doctor can allow me to go home?" Further to that she expressed the longing for family togetherness, which she was missing. She also needed it as a suitable environment for dying. She said, "Yes, being away from home, and dying in hospital." The loneliness of being away from home was expressed on her face, and it could be seen she wanted to die at home.

On the 9th March, she expressed her need for company, and that loneliness brings worries in her mind. She said, "When you go, all the thought about my children and husband come "flooding" my mind, and it sort of drowns me in a painful loneliness." That was the last time she expressed her family worries, until her death on 5 April.

## FAMILY SUPPORT TO PATIENT

Sibongile's husband came to see her once a week. The children came on Saturday as they were schooling. The husband expressed that he was working, depended on public transport, and that the busfare was high. It was two rands a single trip.

Sibongile was asked on 24 February whether her family relationship was good at this time. She said:-

P: "Yes, they are even trying to perform some customs."

N: "Can you relate to me how?"

P: "On my passout in December, I got a chance to have a certain custom performed. I quarrelled with my late mother who died in October, 1987. This quarrel also involved my sister-in-law. My aunt prompted me to perform this custom of pouring each other water (forgiveness) as I seem not to be getting better."

N: "How was it performed, then?"

P: "My father provided a goat and my aunt provided another. The Zionist pastor presided over the ceremony. He prayed and then allowed my elderly uncle to talk to the ancestors, as he knows how to talk to them. He spoke to my late mother to inform her that I was apologising."

N: "Did you feel better physically and spiritually?"

P: "I felt spiritually better and felt my mother had accepted my apology."

I felt this was the most valued family support received.

The family was asked as to what strengthened them in such troubled times. The husband said, 'Well, Nurses we pray together and the warmth of the family spirit of sharing our feelings about her being so ill, are put to the Lord our Saviour.'

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

In the above quoted incident of the patient being helped to settle a spiritual dispute, is seen as both a christian and traditional preparation for a peaceful death.

Sibongile was asked, "Does your faith help you at this time?" She said, "Yes, it does. - I trust in God and I pray that He strengthens me, and He does." Also her mother informed me, on 8 March, that Sibongile had told her, she had no hope of survival, and was just praying that God takes her soul and relieves her from pain and suffering. Sibongile in that faith even believed she could undergo an operation. When the operation issue was debated with her, she felt her mind was sick to have thought of an operation. She said her mind was in a dark cloud, had no hope for her own future, except for the hope of meeting her Lord.

On the 11th March, when she was still in her correct senses, she complained of her offensive odour. At the end of this conversation, I suggested that we pray together. She welcomed this. We held hands, and she prayed that God blesses her, as she was about to come to Him. She also prayed that God blesses me.

#### ATTITUDE OF CARE-GIVERS IN INFORMING PATIENT ABOUT DIAGNOSIS

The doctor and the researcher were positive about the patient being informed about the diagnosis. The nurses in the ward were negative - felt it was not good she was told.

#### DISCUSSING DYING WITH PATIENT

Doctors:

The doctor from the very first encounter with the patient expressed that the disease she had was incurable. The patient stated that this relieved her from her anxiety. This was the expression that she appreciated the discussion about her condition.

Nurses:

The nurses were afraid to discuss dying with the patient. The patient was asked whether nurses discussed her condition with her. She said, "They come twice a day to ask me how I feel. I tell them and they write down, and reassure me that I will be better. They are very kind."

Sister was asked how they assisted the patient. She said, "We just give terminal nursing care."

N: "Do you discuss with her dying and how she feels about it?"

Sr: "O! No, that is difficult. How and where could I start?"

## Family:

The husband informed me he discussed her condition with her. It was expressed as a dark cloud that had befallen their family. The husband told me he tried hard not to express his feelings to her, or even to appear worried, as that would disturb her. The mother even explained that it is not Zulu culture to discuss dying with a patient as that would finish her up. Sibongile seemed to have initiated the discussion on dying, the mother ignored or avoided this discussion. So, all the family felt at ease to discuss their feelings and the signs of impending death they saw in Sibongile with me, but not with her. They informed me they discussed the impending death at home as a family (including the children).

## FAMILY REACTION TO PATIENT'S DEATH

There was acceptance in the family before she actually died. The precedence to that is thought to be associated to the recurrence of cancer in the family. It sounded like, even before the doctor gave the diagnosis, Sibongile's illness signs and symptoms were clearly understood to be that of cancer, and that spelt out death.

In March, when her condition was very low the mother that came to visit her for the first time, just accepted she was dying. The husband also spoke of her in the past tense - "She was such a good wife."

On the 9th April the family had not received the death news of 5th April. The husband was not noticed as he walked into the ward. He

went in, found an empty bed, returned to sister, and said, "So, she is gone nurse?" As he was escorted to the mortuary, he said to the nursing assistant, "O! But, she rested. O! My children are going to grow up without their loving mother."

The family was met at the mortuary on the 12th April.

N: "I felt I should meet you, as we have been united by Sibongile, to say I am with you in your sorrow."

H: "O! Yes nurse, she died, but actually she rested and has gone to meet her late mother."

Bro: "Yes, Nurse she rested. I expected that you shall be with us in our sorrow. You have become a close family friend, or rather you had become sisters with Sibongile, and us. We thank you very much for your concern. Well, she rested from the pain and suffering."

N: "Yes, I do."

He then explained the whole issue. He was asked whether a confession to the pastor was not enough as they were Christians. The husband responded by saying, "It must be both. You link to God through prayer and ancestors through slaughtering custom."

The husband and the two brothers assured me everybody at home had accepted her death, except for the children who were upset.

## CARE-GIVERS REACTION TO PATIENT'S DEATH

Sister felt it had been good she rested from the pain and suffering, and thanked God for that. She felt her life was painful, and was aggravated by the offensive smell. Sister was asked about her evaluation of the care they rendered to the patient. Sister felt that she and her nursing team and the doctors tried their best. The other nursing team members said the same. The nursing assistant also added that Sibongile was at times too difficult to nurse. She felt this was due to the continuous pain she had.

The ward doctor came along, as we talked, and said:-

D: "Matron, your friend died, and I hope you shall accept it. You were miserable when that one died in March (Thelats)." (Doctor talking as he passed, and patted me on the shoulder).

N: "Thank you, doctor for your care, of my friend."

For me it was another loss of a person with whom I had developed a strong relationship of trust. We missed each other just over a weekend off - now it was forever. Despite those feelings, I had to be strong to support the bereaved family who had put their trust in me.

## DEATH RITUALS PERFORMED

The elderly uncle had brought the ziphuf-macropnease twig for taking the spirit home. Sibongile was buried at the Ngwelezana Township cemetery, to avoid the recurrence pollution of cancer in the family. I noticed that when we went out of the mortuary the uncle called,

"Sibongile, it is your uncle Moses, we are now going to put your body where it is going to rest. Let us go." As the coffin was put in the bakkie he spoke to inform the spirit. When the grave had been filled up, he said, "Sibongile, we are now going home, to your own family and your own ancestors." He kept his silence from the mortuary. There were ten neighbours who had come with them.

It was not possible to go with them as I had not been informed of the funeral arrangements in good time. So, I asked the brother to tell me what had been done at home, and had to be done. He said they had slaughtered a goat, made Zulu beer, and placed this in the late mother's hut. When they arrived home, they had to wash hands at the gate, with water to which stomach contents and bile had been added. The twig carried by the uncle was to be placed in the same late mother's hut, where there was Zulu beer and the meat. The reason being that is where the ancestors reside, and Sibongile would join them. They were then to eat cold goat meat and dumplings. Males and females were to eat in different huts.

The husband further added that he was going to first go to the river to bath. He would then have his head shaved outside the fence, on arrival home. This was all to be done to cleanse him of the pollution. The children were to have their heads shaved, outside the fence, on the following day. The children were to wear royal blue cloth neck strings, and the adults a mourning cloth. They were all to remove the mourning sign at the second washing of hands ceremony, except him as the husband who was to remove it at the end of the year.

I asked when the second washing of hands would be, and was informed on 12 May, as it was a public holiday. They had also decided to shorten the period of three months, as they feared the recurrence pollution. I informed them that I was to join them.

On the 12th May, I arrived at Sibongile's home at 14h00. I had such a warm welcome. I was introduced to everybody - family, neighbours, and the congregation. I was told everybody had accepted the death, including the children. They were happy with the aunt. I was informed that they had slaughtered a goat, and made Zulu beer. The children and the adults had had their mourning signs removed early in the morning. They were then burnt outside the fence by the old lady. I was informed that on second thought, the family felt the husband should also remove the mourning sign, in fear of recurrence pollution. He was to remain mourning inwardly for a year, and could not get married in that period.

A prayer was conducted in a big rondavel by the Zionist pastor. He prayed both to God and ancestors. After that there was feasting on meat and dumplings. There was also Zulu beer.

When I left, everybody thanked and blessed me, as well as the greetings and blessing for the ward nurses and her doctor. They were thanked in return, for the friendship and relationship that had been established. I asked them to call via my office to greet me if they happened to come to the hospital.

## CASE NO. 5 : MISS BUSISIWE X.

## INTRODUCTION

Miss Busisiwe X., was a 30 year old single woman. She was a mother of two children. She was hospitalised on 17 February, 1988. She had been previously admitted in June 1987 at King Edward Hospital. She was admitted from Umlazi, where she had relatives.

## ON ADMISSION

Busisiwe was admitted in a very ill condition on the 17 February 1988. She was complaining of lower abdominal pain, dysuria, constipation and vaginal bleeding. She was in a normal mental state and partially dependent.

She was seen by the doctor who diagnosed her as advanced cancer of the cervix - terminal state. She was ordered intravenous fluids and sedation for the control of pain.

## FAMILY BACKGROUND

Busisiwe had a brother and sister-in-law who were her guardians. They lived at Mandini. They had three children. Busisiwe's two children stayed at Mandini in the care of her brother and his wife. Their parents had died.

Busisiwe told me that the father of her children had failed to pay lobolo. Her brother was fed up with her for rejecting the father of the children. So, she also felt happy when he failed to pay lobolo. Her children were well cared for at her home by the sister-in-law, although her mother had died. She said, she had nothing to worry about.

The patient said she lived at Hluhluwe farm, and had been employed as a farm labourer. She had not been working since May 1987. She, however, continued to live there at the compound with her boyfriend. She enjoyed compound life. She rarely visited home.

Busisiwe regarded her brother and his wife and all the children as the family unit. She told me that as she was naughty, - not willing to return home and staying at the compound - her brother was really fed up with her, and rightly so. She said:-

P: "Well, I am naughty! I was once assaulted at the farm compound, in December 1987, where I stay with my lover. My brother never came. I sent a message but he did not come, even though he has a car. When I recovered I never went home up to now. But also, my mother has died, and why should I go home?"

N: "Don't you miss your children?"

P: "Yes, I do in a way. It is just that I know they are well cared for. Of course, the supposed good man (father of her children), as far as my brother is concerned, failed to pay the lobolo my brother wanted. He also did not support me. You know, each time I see those children, they remind me of that stupid man. Let us leave that, nurse!"

N: "Does your lover visit you?"

P: "Nurse, that one makes me sick! He will never come to the hospital to see me. Last year I was admitted twice, he never came. Even now he has never come to see me, but he knows I am here."

We ended up our discussion there. She was to be given the ward stationery to write to her brother, as she said he did not know about her being admitted.

She accepted my advice of writing to her brother. She said:-

P: "Thank you very much. It helps to discuss with other people. I would have remained here in the hospital without them knowing, and yet they are the people to bury me the day I die."

Busisiwe had passed standard eight and was doing some kind of record keeping at the farm where she worked. She and her family belonged to the Zionist Church.

## RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

The patient welcomed and appreciated the manner I had introduced myself. She agreed to being interviewed for research purposes. She gave a verbal consent and saw no need to sign a consent. When I asked to use a tape recorder, she frowned, and asked whether I was a detective. She totally refused the tape recorder.

Busisiwe gave me the family background in this first encounter. She was relaxed, and seemed to be an easy-going person or rather, took life easily. Her face had a number of scars, which she said resulted from assaults.

## ILLNESS HISTORY

### Previous Illness

Busisiwe had been ill from late 1986. She had lower abdominal pain - a sort of crippling pain. She was treated by a number of witchdoctors for several months. She was also sent to the sangomas to hear what caused the illness. The sangomas said she jumped over some sprinkled bad "muthi" (medicine) on the path, meant to bewitch her. The illness then got in and went up her legs to the lower abdomen, where it settled and implanted itself. She had been treated with mixtures and enemata which was meant to dissolve this implanted disease. She referred to the disease as if it were a lump. All this treatment proved a failure.

She then went to three different doctors at Mtubatuba, at different times. At that time she had vaginal bleeding on and off. She was treated with injections, tablets and mixtures. She did not see any improvement in her condition. She further developed a watery burning vaginal discharge.

Busisiwe then went to Umlazi to visit relatives and found her way to King Edward. So, in June 1987 she was admitted, referred by a Durban private doctor. During that admission doctor told her she had cancer of the uterus. She had radium therapy for ten days and was discharged for ten days, whereafter she was to return.

#### Present Illness

Busisiwe did not return to King Edward after the ten days. The doctor had said she was to alternate ten days treatment, on and off treatment for ten days - but did not say for how long. She said, "Hey, nurse that X-ray treatment is not a joke." She admitted it is the painful experience of treatment that made her not return for further treatment. So, she went to be treated by the witchdoctors who claimed they could treat cancer.

So, on 17 February she came to Ngwelezana with a King Edward out-patient's card. She now had continuous vaginal bleeding, lower abdominal pain with a bearing down desire, dysuria, loss of weight and appetite, and felt helpless.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was told by the doctor at King Edward, in June 1987 that she had cancer of the uterus. When asked what she understood about cancer, she said:-

P: "Doctor said I had cancer of the womb." (She paused for a long time).

N: "What do you understand about cancer?"

P: "Well, the doctor at King Edward said it is a very bad sore inside. I can feel the painful sore inside here." (Pointing at her lower abdomen).

N: "What did he say about its treatment?"

P: "He said the treatment is a strong X-ray machine for ten days, and then ten days off the machine, but did not say for how long."

N: "So, did you understand that this treatment shall go on until the sore heals up?"

P: "No, it seems it will never heal up."

N: "Why do you feel like that?"

P: "We were many there, some having had this treatment for years, but in vain."

N: "Did you perhaps ask the nurses?"

P: "They do not explain anything to a patient. They come and ask how you feel, they write on your chart and pass on."

In my discussion with Busisiwe, I found out that she had made up her own conclusion that cancer is incurable. When I asked whether she trusted that doctor could cure cancer, she said:-

P: "The doctor can suppress cancer, but it starts all over again. I think it goes on like that until one dies."

Sister in the ward informed me that she heard Busisiwe speak to another patient with cancer, that she feels forsaken by God to suffer from this disease.

The patient often focussed on her bodily changes, and called cancer a terrible killer. When she was very ill just before her death, she felt and saw death coming to steal her. She had diarrhoea and she explained it as being caused by the tumour in her lower abdomen.

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

Busisiwe informed the family about her diagnosis after discharge from King Edward. The treatment as was proposed by the doctor was discussed and they opted for the witchdoctor's treatment.

I met the family only once during her hospitalisation, on 28 February. Her brother explained to me that Busisiwe was bewitched. The illness had got through the feet, and went up to the lower abdomen and formed a lump. She had lost weight and was emaciated. He was happy that she was in hospital, as the witchdoctors had failed to treat her.

The brother said that he understood that his siter's condition would never improve. She was going to ultimately die. He said as he had seen her so thin and helpless, he thought she was dying. He expressed his worry about her children. When I asked him whether Busisiwe has ever cared for her children, he said, "No, they are my burden. I was hoping she is this type that takes long to mature, and that she will care about her children. Now, there she is dying, and they are my burden forever. But the children also do not care about her." He was encouraged that children will grow to be good if they are brought up by people who love them.

#### PATIENT'S RELATIONSHIP WITH ALL CARE-GIVERS

##### Doctors:

The patient spoke positively about the doctor at King Edward. She was happy he told her about her diagnosis, and the course of treatment. On the 27 February, she asked the doctor here at Ngwelezana, to open her up and excise the painful lump she felt in her lower abdomen. Doctor told her the tumour had become very extensive, and that it would be dangerous to remove it. She positively accepted doctor's advice.

**Nurses:**

The report writing by nurses both at King Edward and Ngwelezana Hospitals, was negatively perceived by the patient because it was not explained to her.

On the 21st February when she was asked whether nurses did all she expected them to do for her, she said, "The nurses are very good to me and the other patients, too."

On the 24th February she was cross because the doctor did not reach her bed during a ward round. When I enquired about this from Sister, she explained it was not her doctor. Busisiwe was asked whether she asked sister; her reply was, "No! These nurses feel big when they walk and speak English with the doctors."

The nurse in the ward, the day supervisor and the Night Superintendent never discussed with the patient her condition of terminal illness.

**Researcher:**

A good relationship of trust and confidence was established between the researcher and the patient on the first interview. The patient was open to say she did not like the tape recorder, she told me her weaknesses, and gave a clear picture of her family relationship.

**CARE-GIVER'S SUPPORT OF FAMILY****Doctors:**

Never met the family.

**Nurses:**

The family came only once. On that visit of 28 February, they were encouraged by the nurses to visit Busisiwe regularly. They reassured them that she would recover. Doctor did not talk to them.

### PATIENT'S FAMILY WORRIES

Busisiwe seemed not to worry according to what she verbalised. I, however, felt the facts she gave about her family set up were worrying her. Her admission that she was naughty, that her children reminded her of their father whom she disliked - were her feelings of guilt. It seemed not caring for the children was her guardian's punishment, as they had insisted she should not reject the man. Her immediate acceptance of the advice to write home, was seen as a submission to a need for family support, in such a very ill condition.

### FAMILY SUPPORT TO PATIENT

The prompt response to Busisiwe's letter of 21 February was seen as a positive attitude or concern about her illness. Busisiwe was very happy after their visit. She heard of her children, which were well cared for.

### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

Busisiwe admitted it was a long time since she went to a church service. The day we discussed her fears about the impending death, I asked:-

N: "When you get shaken up like this, what strengthens you?"

P: "It is faith in God. I was so ill yesterday that I remembered to pray."

So, at the end of our conversation I suggested that we pray together. We prayed together holding hands. In her prayer she asked the Lord to take her as she was suffering the pain. The following day, on 2nd March, she was critically ill. I went to see her at 06h50 and we prayed together. I asked her whether she prayed during the night. She said she had prayed right through the night whenever she was awake. Busisiwe died the same day at 15h00.

#### CARE-GIVERS ATTITUDE IN INFORMING PATIENT ABOUT DIAGNOSIS

The doctor was positive to informing the patient about her diagnosis. All the nurses except one, were negative to patient being informed of her diagnosis. The only positive nurse said:-

Sr: "Yes, I think it is good for the patient to know her diagnosis. One can plan for one's future."

N: "Are you able to disclose the diagnosis when doctor asks you to?"

Sr: "Yes, I once did it, and the patient who was a school teacher, appreciated being told. She felt she was able then to plan the future of her children."

N: "That was good of you. Did the patient discuss freely about her diagnosis?"

Sr: "No, she did not. I don't know whether it was the fear of death, but also I did not know how to approach her. I think we nurses lack the skill. But also, matron, how does the patient feel if she has cancer?"

N: "We can only know when we talk to them."

#### DISCUSSING DYING WITH THE PATIENT

The doctor informed the patient about her diagnosis. The nurses feared even to interpret that the tumour had become extensive. A sister overheard her talking to another patient that she felt forsaken by God, but did not say anything. When sister was asked:-

N: "What did you say to her when she said she was forsaken by God, to suffer from cancer?"

Sr: "I just kept quiet and felt sorry for her. She is so young."

The other sister said:-

Sr: "I try by all means not to discuss her illness, except when interpreting for doctor."

N: "What is it that you exactly fear?"

Sr: "In case the patient asks me whether she was dying. You see, I do not like to tell lies to the patient. It would be better if we were taught how to talk to such patients."

The family commented on Busisiwe's condition, and were asked:-

N: "Did you discuss with her about her condition?"

Bro: "No, we did not. I thought of commenting about her weight loss, but I felt she was very ill. It was going to discourage her. but, she is 'finished'!"

N: "Is there another reason for not discussing dying with her?"

Bro: "Nurse, it is not our culture as Zulus to discuss such issues with a very ill person."

The researcher discussed dying with the patient. On 21 February the patient said that she understood that cancer goes on, until a person dies.

N: "How do you feel about that, that a person ultimately dies?"

P: "I fear that thought. Nurse, is it not better that doctor does a hysterectomy?"

The patient appeared to be anxious. So I dropped the topic, and we talked about the possibility of the operation. This ultimately involved the doctor on 27 February, when sister feared to interpret that the tumour had become very extensive.

On 1 March, the patient's condition became critical. She bled per vagina profusely and had diarrhoea. It was the day she said she remembered to pray.

N: "What frightened you to remember to pray?"

P: "It is the fear of passing away."

N: "How did you exactly feel, to think you are passing away?"

P: "I became very weak, just helpless. You see if you have no strength to breathe, you cannot live."

N: "Yes, I understand that should be fearful."

P: "You must pray with me before you go."

#### FAMILY REACTION TO PATIENT'S DEATH

The family was met at the mortuary after the patient's death, on 7 March. The brother said, "Nurse, she was very ill. We expected it." The ward sister reported the same, that they seemed to have expected the death and accepted it.

#### CARE-GIVERS REACTION TO PATIENT'S DEATH

The doctor, nurses, supervisors and the researcher accepted the patient's death. The nurses and the supervisors pitied the researcher for the death of her patient.

## DEATH RITUALS PERFORMED

Busisiwe was buried at the Ngwelezana cemetery, on 10 March. The brother was asked about death rituals. He told me they had slaughtered a goat and made Zulu beer. This was placed in what used to be the late mother's hut, as they regard it as the ancestors' room - where they reside. They had brought the Ziphuf-mucronaea twig, for taking her spirit home, to join the ancestors.

When we left the mortuary for the graveyard, the elderly aunt put the twig on the coffin, and said, "Busisiwe, Busisiwe, it is your aunt calling you. Let us go. We are going to put your body to rest, and then go home." She then remained silent. When we got into the bakkie, she told the spirit, and when the burying was complete. She then said, "Busisiwe, we are now going home."

The brother informed me the twig was to go into the hut with meat and beer. The aunt was going to tell Busisiwe's spirit, they had arrived home, and ask her to join her ancestors, and ask her to be a good protecting ancestor. The brother said on arrival they and their neighbours would wash their hands at the gate entrance, with water to which had been added the stomach contents and bile. This was the first washing of hands ceremony. They would then feast on meat and dumplings and disperse. The next morning, all the children and adult males were to shave their heads outside the fence. This was all for the washing off of the death pollution. The family members were to wear a black mourning sign.

The brother was asked why they did not take the corpse to bury at Mandini. He said they are worried about this cancer, that they might be "dragging" home a misfortune or pollution. They strongly believed she was bewitched and it would cause recurrence pollution.

The brother was asked whether there was still to be other death rituals performed later. He said they would perform the second washing of hands ceremony early, for the fear of recurrence pollution, on 7 May.

On 7 May, when I arrived at noon, the family had washed their hands with water to which was added bile and stomach contents of the slaughtered goat, and Zulu beer had been made. The children and all adults had removed the mourning signs, which had been burnt by the elderly aunt outside the fence. I was called by the elderly aunt to wash my hands, as I was her nurse and like her mother.

The family and the neighbours assembled under the shade, the pastor conducted the prayer. He prayed to God and talked to ancestors as well. Meat and dumplings were served in separate huts for males and females.

At 15h00, I thanked the family and told them I would not return again. They thanked and blessed the researcher. They sent, through me, their greetings and blessings to the rest of the care-givers.

#### INTRODUCTION

Mr. Selby X, was a 32 year old male, from Hluhluwe in Hlabisa district. He was single, but had a 8 year old daughter. He was hospitalised on the 4 April, 1987.

#### ON ADMISSION

Selby had had several hospital admissions before we met in April, 1988. In December, 1987 he was admitted as a transfer in from Hlabisa Hospital. He was re-admitted 19 March, 1988 at Ngwelezana. On this admission of 4 April, 1988 he had been admitted in a very ill, helpless condition. He was complaining of difficulty in swallowing, abdominal pain, constipation, vomiting, and dysuria. He was also very dehydrated.

The doctor's notes reflected the same problems and ended up with a tentative diagnosis of cancer of the stomach and oesophogitis. The doctor prescribed intravenous fluids and medication. On the 12 April his diagnosis was revised to severe inflammation of the stomach.

#### FAMILY BACKGROUND

Selby was the first born in his family of four illegitimate children. His siblings were a 24 year old brother and a 26 year and 18 year old sister. They stayed with their mother, at the mother's home. His grandparents had died, and their uncle was married and had his home in the same Hluhluwe district. His father had married another woman, but stayed in the same Hluhluwe area. They were called by the father's surname, because the appropriate custom had been performed. The Zulu custom is that the father pays lobolo for the illegitimate children. When the father's people leave home to send lobolo, they inform their ancestors. This lobolo is six (or less) head of cattle. A slaughtering ceremony is performed to inform the ancestors of such a move. The children can then be taken by the father or may remain at their mother's home. The procedure of informing ancestors in both families ensures that the position of such children is normalised, according to Zulu culture. They will then have the care and protection of ancestors.

The whole family was educated, Selby having passed standard eight. His brother and sisters were matriculated. The mother had been a privately paid teacher, and had stopped working due to ill health. They were Roman Catholic by religion. Selby had been out of employment for about two years due to ill health.

Selby's eight year old daughter lived with her mother, at the mother's home. His girlfriend/mistress was a school teacher. Her home was near Selby's home, so that the child regularly passed the father's home to greet the father and grandmother. Selby's father supported them and came to visit them.

#### RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

This was on the 11 April, 1988 at 13h45 in the male surgical ward. He looked very emaciated, miserable, and a very reserved person. When I had introduced myself and stated my request of interviewing him for research purposes, he smiled and relaxed. He also commented that it would be nice if all nurses were polite like me. He gave a verbal consent for research, saying he trusts a nurse and a doctor. He refused the tape recorder, and stated no reason.

The patient asked me where I had come from, since he had never seen me during his previous admissions. I explained that I was one of the senior nurse administrators, and I worked in the administrative offices. He smiled, and said it meant he was honoured to have me come to interview him. We both laughed. We then discussed his family background, as given above.

It was noticed that he was a soft-spoken, jocular, well-mannered man. When I greeted him, he quickly tried to button up his pyjama top and tried to sit up. He was assisted by sister and myself. He thanked us for assisting him.

## ILLNESS HISTORY

### Previous Illness

Selby stated that he had not been well as from the beginning of 1986. He had a discomfort on swallowing, and epigastric discomfort after meals. Later, in 1986 he realised he was losing weight. He, however, did not think he was ill, and never sought any treatment.

### Present Illness

In mid-1987, the dysphasia and epigastric discomfort turned to be very painful. He went to two private doctors, at three months intervals, at Mtubatuba. Each one told him he had sores in the stomach. He was treated with injections, tablets, and mixtures. In between each doctor's visit he expected to feel the effect of the treatment, but all in vain.

After all these trials, in December, 1987, he discussed his illness with his family and told them he wanted to go to Hlabisa Hospital, their regional hospital. The doctor at Hlabisa told him he had to come to Ngwelezana Hospital. The Doctor said he needed investigations and treatment by a senior doctor who have better equipment for that. He gladly came to Ngwelezana. Doctor told him before these examinations that he did not want to guess his diagnosis.

After these investigations three doctors came to see him. He was told that he had a tumour in the stomach. The doctors told him this required an operation, and he consented straight away. He underwent the operation. He felt very weak post-operatively. The operation scar was also very painful. On questioning, he felt it was dysphagia, rather than the operation scar. He gradually recovered, and by the 16 December, he could take a fluid and soft diet. So, he was discharged home for Christmas, with a warning that he should call back immediately when he felt sick.

In mid-January, 1988, he became very ill and could not take anything orally. He went to Hlabisa Hospital, and was immediately transferred to Ngwelezana Hospital.

Selby was asked what he thought caused the pain. He said:

P: "Well, we have discussed that as a family, and we think it is "idliso". I was bewitched. This idliso must have been working on me slowly, like slow poison, since 1986 when I had the discomfort. I now think had I gone to the witchdoctor then, he could have given me an emetic, to vomit it out".

N: "If doctor is able to cure you, will you still go to the witchdoctor?"

P: "No, nurse, I would just slaughter a beast to thank the ancestors".

N: "Why not thank the doctor, Selby"?

P: "You should understand this as a Zulu. When we are alive we always have a protecting hand of our ancestors. You see, my ancestors are aware of my being here. When I left home, my mother informed them I was coming to hospital, and asked for their protection. So, whatever doctor does is going to be successful. I shall thank doctor when I leave the hospital. The slaughtering ceremony is the method of thanking the ancestors".

N: "I am happy you are clear about your culture, and that you have confidence in your doctors".

Selby remained in hospital until mid-February. He was discharged home and was to come for check up once a month. When he came in March, he was admitted and discharged after two weeks. For each admission in January, February, and March, he was put on hyper-alimentation, regained his strength and was discharged. In the beginning of April he was ill, but delayed taking a decision to come, as he was fed up with hospitalisation.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

In December, 1987 the patient was informed of his diagnosis after the barium meal and gastroscopy. On his January re-admission doctor told him he had cancer. He only told me he knew his diagnosis, when I asked him on 12 April at 13h25, which was the second interview. He was just relaxed when he said it.

N: "Has doctor told you what is wrong with you?"

P: "Yes, nurse, he told me this morning that even though he had informed me in January that I had cancer, the biopsy results are back and it is not cancer. (He held up his thumb and exploded in a big laugh, and I rejoiced with him). Look there in my chart".

N: "These are surely good news, Selby. But tell me, when you knew you had cancer, how did you feel?"

P: "O! Nurse, it was a horrifying experience. I was sorry for myself, my mother, and my child. Each time I was alone I felt God had deserted me, especially when the pain was severe. When the pain was over, I would think that, well death comes to the young and old, and would pray and feel strengthened. But nurse, what was worse of it all was pain. Pain made my spiritual and emotional suffering about my diagnosis and pending death, even worse".

- N: "So, when the pain was off, you did not think about death?"
- P: "No! No! - I thought of death all the time. I was anxious all the time. O! But today, I am happy - I have no cancer"!
- N: "I am happy with you Selby. So, you are now sure you shall be cured."
- P: "I might or I might not, but at least I won't be knowing I am going to die. Death will just "steal" me like for any other person, and as God wanted it to be".
- N: "Tell me, in April what made you delay coming to hospital?"
- P: "To tell you the honest fact, I did not see the need for hospitalisation when I knew I was going to die. I prepared to die at home".
- N: "Selby, when you had those horrifying thoughts about cancer, were you happy with doctor having told you about your diagnosis"?
- P: "Yes, because I kept on asking him whether I did not have cancer. He was reliable because he said he strongly suspected cancer, but was awaiting the biopsy results, which as you see were negative. If cancer was confirmed, I think I would have planned for my death. Well, it is just that I am poor, and have no property or wealth to distribute".

Although cancer was excluded Selby's condition deteriorated, and always complained of pain on swallowing. On the 21 April, he was a bit better, and I found him basking out in the sun at 08h30.

- N: "It is good Selby that you ae sitting out".

P: "But what is more good, mama, is the company of other people. If you are confined in bed being helpless, you just see death crawling towards you and feel very anxious".

On the 28 April, the Night Superintendent informed me when I arrived at the hospital at 06h30 that Selby's condition was critical. He had been vomiting the whole night. An intravenous drip had been put up, but he remained very dehydrated. She ended up by saying it seemed he was not going to make it that day. Selby had expressed his wish as if I could come early to see him. (I often visited him at lunch time, between 13h00 and 14h00).

After taking the night report, I proceeded to the ward, at 06h45. He smiled when I came in. He told me about the vomiting and the abdominal pain. I held his hand and felt and massaged the abdomen. He smiled and said he was happy then, I could go.

Selby was very ill, and required to be transferred to the intensive care unit at 12h30. He was vomiting yellowish fluid, and with hiccough, and very restless. I was phoned and informed about his transfer by the surgical ward sister. At 12h50 I was phoned by the intensive care unit sister informing me he was in her ward, and that she had been given a report he was my research case. I told sister, I was to see Selby at lunch time, unless he wanted me there and then. Sister said, he looked miserable and had been tipped by the other sister that his attitude and condition sort of normalises when I am or has been with him.

At 13h10 I walked into the intensive care unit and Selby saw me, and tried to force a smile. He was vomiting and troubled by hiccough. I assisted him to rinse his mouth. I wiped his face with a damp towel, turned his pillow, and lubricated his lips with vaseline. His skin was dry and hot. Selby said:

P: "I fear as if I am going to die".

N: "What type of feeling did you have to think you are dying?"

P: "All my inside feels upset, I have no vigour - just a helpless bunch, vomiting this bitter substance, my mouth is bitter. It feels as if all of myself is surrendering even my will power".

On further discussion, I learnt that although cancer had been ruled out, Selby felt there was something very wrong in his abdomen. He was very prepared to go to the operating theatre. He actually verbalised that he thought the tumour had grown again in the stomach. His mind and thoughts seemed to be focussed on the dysphagia, epigastric pain, which was his initial diagnosis known to him. So, on 5 May he was prepared for the operation. He became very anxious, and called for me at 07h40. He reached for my hand, and he tried a firm grip, so I responded. He said that he was afraid of the operation, as he might not survive. He further said, "I think I am going to die unless a miracle happens". He was assisted in making his own decision, and he collected himself and decided to go for the operation.

Selby ultimately went to the operating theatre on the 6 May, at 13h50, and I accompanied him on his request, with the doctor and sister, as he was wheeled on his bed. As we went along he asked me to tell doctor not to tighten the sutures, as they did for the first operation in December, 1987. Selby did not recover to be informed of his final diagnosis. He was on the respirator, post-operatively until his death on the 16 May, at 10h15. His final diagnosis was a perforated diaphragm, perforated ileum volvulus and a gangrenous bowel

#### REACTION OF FAMILY TO KNOWING PATIENT'S DIAGNOSIS

Selby's aunt was the first family member I met on 18 April. Selby had informed me that his father had been to see him on 16 April, and he had informed him about me, and the father sent his greetings. This aunt had heard of me, so she was happy to meet me in person.

The aunt was happy that cancer had been excluded, but said:

Aunt: "We have seen Selby. He is so happy it is not cancer, but whatever it is, he is so thin, that I don't see him surviving".

N: "Yes, he has lost weight, but he is fed on intravenously with very nourishing fluids."

Aunt: "We are all worried about him. This "idliso" has really ruined him. Continue to keep an eye on him for us all. He has such trust and confidence in you. Thank you child, we must not miss our bus".

N: "Thank you aunt, I shall keep an eye on him".

Selby's condition sharply deteriorated as on 28 April (as already stated). The mother and aunt came to visit Selby on the 2 May. After seeing him, Selby asked sister to accompany the mother and aunt to my office. After greeting, the mother said:

M: "Nurse, Selby is very ill. He is finished. He is just skin and bones. He says he is going to undergo an operation. Tell me, nurse, what is doctor going to operate on? A skeleton"?

N: "Well, mama, he is very ill. It seems there is something that has gone wrong in his abdomen".

M: "I understand so, and that doctor is going to look inside with his instruments, and operate if it is necessary. O! But it might be the end of him. At the same time doctor cannot just look at him suffer like this. Well, my child if he dies, it will be God's will".

N: "Well, mama, that is acceptance of reality,-

M: "O! As for my child! Let me go nurse!"

The mother, sister, and aunt came to see Selby on 5 May, the day of the operation. She gave me the illness history, that was caused by the "idliso". She said, "the idliso" had grown up as a tumour, referred to by doctor. The "idliso" tumour has been sucking up his blood to fatten itself, at the expense of her son's life. She stated that when this "idliso" illness started Selby always had a choking feeling just at the sight of meat".

On departure I asked the mother as to what strengthened them at this difficult time. She said it was prayer. They prayed as a family, and the priest and the neighbours came home to pray with them. Before they left I prayed with them.

The mother seemed to accept that her son was definitely going to die. She anxiously said, "I am so sorry about my son. He has been so obedient to us all at home, and the neighbours. As I am here, I have travelled free - my neighbours gave me bus and taxi fare. Everybody in the neighbourhood misses Selby. O! Nurse, his feet are cold! That is not a good sign, my child." I asked her what it meant. She just ignored my question and just talked to herself, saying, "Hmmm.... I don't see him surviving." She then raised her head, and spoke to me, "I did everything for him, my child. I took him to the various doctors, and various witchdoctors. I spent all I could for my son. Even if he dies, my conscious is clear - I did all a mother could, for her beloved son". I praised her for all the efforts, and told her that Selby had told me about it all, and that he was very grateful. She smiled with an expression of satisfaction.

At 13h45 the mother was found at the bedside. She told me that she turned back at the gate, after leaving my office. The nurses and doctors allowed her to remain with her son.

After the operation, when Selby was on the respirator, the aunt and sister came to me from the ward.

Aunt: "Nurse, we have seen Selby. We have lost hope. It is just to wait for the day".

N: "Yes, he is critically ill"

Aunt: "O! My child, I think it is this machine which is keeping him alive, otherwise he is dead. We are just grateful that you have become a family member, and we know that it means he has a sister close to him all the time. That is what eases our tension. We are leaving now".

(The aunt spoke in despair and they were both sobbing).

#### PATIENT'S RELATIONSHIP WITH ALL THE CARE-GIVERS

##### Doctors

Selby was able to communicate with doctors in English. From January the doctors told him what they suspected, and up to the final diagnosis. He appreciated that, and it build up confidence in him for the doctors. On the 14 April, he had this to say about the senior surgeon,

N: "Do you have confidence in you doctor?"

P: "Yes, he is a sincere man. He likes us as his patients, and tells you about your illness, and what he is doing for you".

On the 5 May when the intended operation was discussed, it was the faith and confidence Selby had in the two doctors that made him to give consent. As doctor, sister, and myself wheeled his bed to the operating theatre on the 6 May,

Dr: "Matron, are you sure he understands he is going for an operation?"

N: "Yes, doctor, he does".

P: "My friend, I trust this doctor - he is a man. He always comes with my senior doctor. Tell him that when they suture the operation incision, they must not make the sutures very tight, as they did in December."

Well, Selby never regained consciousness after the operation, to evaluate the tension of the suture line.

#### Nurses

On the 12 April, Selby told me that both the doctors and nurses were kind and caring. On the 14 April, when asked:

N: "How do you show your gratitude to the caring team?"

P: "I verbally thank them".

N: "Do you tell them how you feel or when you need their presence?"

P: "These have no time for a patient. You see when you call a nurse, she does not show any concern for you, you decide to keep quiet".

N: "But if you need assistance, who ultimately helps you?"

P: "Often one neighbour patient if he is better than you".

The nurses said Selby was a quiet patient, but miserable because of the diagnosis. When he had been told he did not have cancer, they claimed he was brighter. On the day Selby was transferred to the intensive care unit, it came out that they had seen me as Selby's pacifier. When I reached the intensive care unit, on that day at 13h10, the bottom of Selby's bed had a sticker written: "If Selby wants Mrs Mtalane called, please do so immediately at anytime of the day or night". This was highly appreciated. Selby smiled and nodded when I read it out.

Selby on two occasions expressed his dissatisfaction about the nurses, especially the night nurses. He was asked:

N: "Do you feel good when you have discussed your illness problems with somebody?"

P: "Yes, I do. It is just that the nursing staff is very busy to talk to us, and they don't care."

N: "Are they so busy not to talk to patients, or do you think it is a negative attitude?"

P: "They could find time. At night when you feel insecure and afraid, they sit in their office."

N: "Thank you, Selby, I shall see how to get that corrected without involving you."

This conversation was on the 18th April, when he had been cleared of the cancer diagnosis. It seems he remained hopeless about the recovery.

#### Researcher

The researcher established a good relationship of trust and confidence in the first encounter with the patient. The patient was confident about expressing his personal feelings about his diagnosis, attitudes of doctors and nurses.

Selby developed dependence on the researcher as a person who cared or as his visitor. This was sensed, and during the week-end phoned to enquire, and he would send back his greetings through sister. On Fridays I went to see him just before leaving the hospital at 16h00, and gave him the weekend Zulu newspaper "Illanga." On Monday, I made it a point to see him before 07h00. On Monday the 18th April, I could only see him at 14h10.

- P: "Hallo, nurse, I have been wondering what happened to you this morning".
- N: "The Head Office official came and we went out to inspect two clinics".
- P: "I see. Otherwise how are you?"
- N: "I am alright and you?"
- P: "I can take fluids and hope to continue improving".

The nursing assistant in the ward, on this day said:

- N: "How is Selby?"
- N/A: "He is always miserable, he hardly smiles. He is better since you started visiting him - he can even smile. Even that other patient you visited in February, became friendly when you had been here".
- N: "Do you think it is the visiting that makes them have a pleasant attitude?"
- N/A: "Yes, some patients are very ill and their families are far to come daily, but your patient becomes sure of your daily visits. Sister also said you discuss with your patients their conditions of illness".
- N: "Was sister suggesting that you also do that?"
- N/A: "I don't know because sister said you have a special gift of talking to people. She said what you are doing is a very difficult task, and it needs a mature stable person like you".

N: "Thank you".

On the 20 April, Selby was in severe pain. As he told me, sister heard, and said she was going to sedate him. Selby grumbled, saying he wondered for how long he was to wait for the sedation had I not come. He then added, O! You are like my real mother".

On the 26 April, Selby informed me that his father visited him on 23 April. He had told him about me, was grateful, and sent his greetings.

N: "I wonder what you tell your family about me?"

P: "I tell them that you come daily to see me, and discuss with me my illness and progress. Perhaps you do not imagine how grateful I am, to have somebody to talk to and confide in".

N: "I am happy to hear that Selby".

At times, Selby was too ill to talk, but he was visited, sat next to him and held his hand, and prayed. He told me one day, he felt sorry for me when he could not talk, but my presence meant a lot.

The patient wanted to cross-check his health decision with me. The day he was transferred to the intensive care unit, he said:

P: "Tell me, is it alright that I go for an operation?"

N: "You made me understand you had taken a decision to go for an operation".

P: "Yes, I did. I feel I must not refuse what is meant to help me".

On the 29 April I saw the patient at 08h15, and told him I was going out of the hospital. He asked, where. I told him for clinic inspection, and that I would be back by 15h00. He queried whether the road was safe as it had been raining. I assured him it was safe. So, at 14h45 I dashed to see him.

P: "Are you back and safe?"

N: "Yes, Selby. In fact I was back at 13h00 and had to do some urgent work".

P: "I like your sincerity in keeping your word. There has been no change in my condition since you left. I have been fighting the drowsiness because I wanted to see you, and not be told you came".

N: "Is there something you wanted to discuss with me?"

P: "No, it is just that I now know you are off Saturday and Sunday. I miss you when you are off".

N: "I shall see you on Sunday, as we are going to a community meeting for the selection of a Clinic Advisory Committee".

P: "So, there is no rest for you - even on Sunday. Your work is really a calling!"

On Sunday I found him propped up in bed, and smiled and said to the nurse, "Here comes my mother!" On the 2 May, Selby reached for my hand, smiling and said:

P: "Come closer, I want to whisper something to you. The nurses have been here around my bed this morning, asking me whether we are related - the whole team, five of them.

N: "What did you say?"

P: "I smiled and told them you visit me because you are studying something. They said, I am bluffing - we can't be so attached to each other just for study purposes: So, I again confirmed I have just come to know you here at the hospital. So, the argument went on, until I said we are related. So, they accepted that". (We both laughed).

On the 6 May I was phoned by sister at 08h15:

Sr: "I am phoning to inform matron, that Selby is very bad this morning. I think he might be happy to see you".

N: "Why do you think so?"

Sr: "He keeps on checking who is coming in, each time the door opens".

N: "How is his mental state?"

Sr: "It is sound. He is just in pain".

N: "Alright I am coming right now".

As I walked in I saw an anxious look he had hiccough, he was groaning, his face so bony.

N: "How are you, Selby?"

P: "I am happy to see you. I have been wondering what happened to you".

N: "O! Selby, I was going to come".

P: "Help me sit up and rub my back. The abdomen is painful".

N: "I see, doctor has been here already. What did he say?"  
(We spoke as I wiped and rubbed him).

P: "Yes, my friend. He said I am going to the operating theatre, after Xray. Is that alright?"

N: "Yesterday we agreed on doctor opening you to see what has gone wrong. We also agreed that we put everything in God's hands".

P: "Yes, I shall go for an operation, because there is definitely something wrong in this abdomen.

N: "Do you feel you need the Holy Sacrament before the operations?"

P: "No, nurse, I will vomit it out, and that is not good".

N: "You are correct. Let us pray together".

We held hands and his grip was firm and we prayed. I left and we agreed on seeing him when he came from the operation. At 13h50, sister knocked at my door, and said:

Sr: "Matron, I am here on Selby's instructions. He says I must fetch you in person and not phone. He says he is not going to the operating theatre before seeing you".

(I got up and went along with sister).

N: "Selby, are you ready to go for an operation?"

P: "Yes, but I wanted to see you first".

N: "Are you afraid or there is something you want to say?"

P: "No, it is just that I feel good, confident, and secure when you are next to me".

(He tried to reach for my hand, and I held his hand)

Dr: "Matron, is he your relative?"

N: "No, doctor. He is my research case".

Dr: "Then research is good. You know he stopped us, as we started wheeling his bed out. He said to me, somebody has to come first".

As he was wheeled to theatre we held hands, until I reached the operating theatre's red barrier line. Selby then said, "Thank you for everything, my friend and mother. Shake hand, God bless you". He turned and faced the other side. I said, "Thank you Selby, for everything too. God be with you during the operation ". He raised his hand, and shook my hand. We parted.

Selby did not return to the ward until I went off at 16h00. I left a message in the intensive care unit, that I be informed when he is back. The Night Superintendent phoned me at 20h00, and told me he was critically ill, on a respirator. On the 7 May, I phoned at 09h00 and spoke to sister-in-charge:

N: "How is Selby?"

Sr: "He is critically ill. The doctors repaired the perforated diaphragm and ileum, and resected a gangrenous bowel which was due to a volvulus. His blood pressure is ranging between 80/50 and 90/50, despite the dopamine drip. He is on a respirator".

N: "Is there any hope of recovery?"

Sr: "Not yet. In fact according to my experience he has no chance. I know that hurts you but I should be honest".

N: "Yes, it hurts. If he is so bad, then get him a priest for the Last Sacrament, as he is a Catholic"

Sr: "I shall do that. Sorry to tell you such bad news, but I thought it is better to put you in the picture.

I continued to visit Selby, held his hands and talked in his ear, until his death on 16 May, at 10h15.

#### CARE-GIVER'S SUPPORT OF FAMILY

##### Doctors

The doctors never met Selby's family. It was Selby who told the family about his good doctors. They then developed a positive attitude towards the doctors.

##### Nurses

On the 26 April, the researcher specifically asked the ward team individually, what they said/discussed with the family. They all said they reassure them, and said they hoped Selby would be better - although they felt he would not make it. Sister was further asked, whether she discussed the pending death. She said, "It is not Zulu culture to do that, as they can also see Selby was dying, it would hurt them".

#### PATIENT'S FAMILY WORRIES

The patient worried about his eight year old daughter, that if he had wealth and property he could leave it for her, as already quoted. He put his trust in the mother.

On the 5 May, Selby spoke openly to the mother about his concern about his daughter, in my presence.

- P: "Mama, how is Sindie?"
- M: "She is fine. She goes via me daily on her way to and from school. Your sister bought her three panties".
- N: "Who is Sindie?"
- P: "She is my little daughter I told you about".
- N: "Do you want to see her?"
- P: "Mama, that is alright, it is too far, for you to travel with a child".
- M: "Selby don't worry about Sindie, she is alright, and is well cared for, as long as I live."
- P: "Yes, Mama - as long as you are alive, and then later?"
- M: "O! But your sisters are there, my son." (Mother sobbing).
- P: "Yes, mama, I trust you than anybody else. Anyway, let us stop the topic, as you are crying".
- N: "Selby, I think you feel good if you talk about it, as well as mama, and myself. Let mama cry if she feels like". (Mother cried openly).
- P: "Well, there is nothing further to say. If my sisters' husband do not want my child, then?"
- N: "Selby, we must look to the bright side of things. These are relatives in your extended family who care. There are neighbours who care to whom you have been good. They have been providing your mother, sister and aunt with busfare to come and visit you. All that fulfills that the Lord God provides. Selby, we said, this morning we put everything to God's hand - He provides".

P: "Yes, He will provide, just as he provided you for my care in my last days - as I see myself in this condition. Why must I be of little faith." (He laughed and stretched both his hands to reach for the mother's and my hand).

I must say this was the most trying event in all these case studies. When the mother cried, Selby looked up straight towards the door. He was calm, the face expressionless, voice clear and steady. The mother went via the office to thank me, for my assistance in the difficult conversation.

#### FAMILY SUPPORT TO PATIENT

The family stayed far from the hospital. The neighbours made an effort to accompany the mother, and to give her money to come to see the patient. The priest also came and he received Holy Communion. He was happy about his father coming to see him.

The family just reassured Selby that he will be better and avoided asking about his feelings, until the mother was caught up in the above quoted discussion about Sindie.

The family included the researcher as a family member, and this was repeatedly verbalised. Selby spoke well of his family.

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

When we discussed how he felt when cancer was queried, Selby expressed that he was in pain, he thought God had forsaken him. When the pain was off, he accepted that people of various ages die, and somehow got strengthened in his faith and prayed. So, obviously pain was a disturbing factor in clinging to what he believed.

On the 28 April, he was very ill, and on discussing how he felt, I asked:

N: "What strengthens you at such a time?"

P: "I pray, nurse. At times the pain is so severe that I just say, O! God, O! God".

The patient reported to me happily about the priest's visit, on 27 April:

N: "Selby, are you praying?"

P: "Yes nurse. I forgot to tell you that my priest came to see me yesterday afternoon, from Mtubatuba. I received Holy Communion and he prayed for me".

N: "Wonderful! How did you feel thereafter?"

P: "I felt strengthened in my faith, as I fear I am going to die. My spirit is good right now, that if I die I shall meet the Lord, and be free from pain, forever".

He spoke pleasantly, and confidentially

It was, therefore, easy for me to say, "Selby, let us pray", at anytime. It was in faith that we put Sindie's future in God's hand. When he went to the operating theatre we put everything to God.

#### ATTITUDE CARE-GIVER'S INFORMING PATIENT ABOUT DIAGNOSIS

The doctors were positive and discussed the patient's diagnosis with him. The nurses were asked at various times, they were all negative. They pointed out that it is not good at all. When doctors were suspecting cancer, Selby was miserable. The researcher was positive and discussed the diagnosis with the patient. Nurses regarded it as a special ability and level of maturity, as already quoted under 6.

## DISCUSSING DYING WITH THE PATIENT

In discussing about cancer when it had been excluded, I asked:

N: "So, as you thought you had cancer, you could not discuss about the pending death?"

P: "I don't know whether doctor could, but I can't speak English fluently. But even if they could, it is not easy to discuss about death. You know, you just don't know who you are, you seem to be in a dark vacuum, and your future is dark. Your life is governed by pain, which gradually and persistantly destroys you. You just don't know whether you are coming or going".

Selby further felt it was good to know about one's diagnosis, as he could have planned for his child and mother. He said it was good to have somebody to discuss death fears with. The patient told me he informed his family he had me to confide in, and was very grateful. Selby described the fear and feelings of pending death, as a feeling of helplessness, all his inside upset, all of it surrendering, even the will power. Death was personified, when he said, "You just see death crawling towards you and feel very anxious".

The researcher asked the nurses whether they discussed dying with the patient. On 18 May.

N: "How is Selby?"

Stud/n: "He is very ill, but cancer has been excluded".

N: "What made him dull before the biopsy results?"

Stud/n: "He was fully convinced he had cancer, and I think he thought he was going to die".

N: "Did you talk to him to establish what were his feelings and thoughts?"

Stud/n: "No, I did not discuss with him, as he was so depressed and the sorrow was written on his face".

The nursing assistant, told me that the patients seemed to enjoy my discussing with them their conditions. They had discussed this with sister and felt it was good but could not do it themselves. Sister on the other hand felt, it is doctor who should do that, it is his duty. The Night Superintendent/Chief Professional Nurse, said:

N/A: "O! No, Mrs Mtalane! If I discuss death with the patient it will make his condition worse".

The sister on night duty said:

Sr: "No, I don't have the courage. I just reassure him that we hope he will be better".

N: "Are you happy to say what is not correct?"

Sr: "I am sure he sees that he is dying. In our Zulu culture and in nursing, we reassure a sick person".

Another sister who had nursed Selby, was asked whether she discussed dying with the patient, she said, "O! No, Matron! I am afraid to discuss death with a patient who sees that he is dying".

The family avoided discussing dying with the patient, but came to the researcher in the office, to verbalise their feelings and their observations about the pending death".

#### FAMILY REACTION TO PATIENT'S DEATH

The family was met at the mortuary on 20 May. It was the aunt, two female neighbours, brother and his friend, and younger sister. They all felt it had been better for him to die than to suffer that pain. They told me the mother had remained at home, she was a bit disturbed. The elderly aunt, whom I had not met said, "They were right to say you have become part of the family. Here you are with us!" They were happy to hear that I would attend the funeral.

#### CARE-GIVERS REACTION TO PATIENT'S DEATH

The doctors, nurses and the researcher immediately accepted the patient's death. They all felt they had done their best for the patient. The doctors and nurses all pitied the researcher about the death of Selby. Sister that phoned at 10h30 on 16 May, said:

Sr: "Matron, I am sorry to inform you that your patient Selby had died at 10h15".

N: "Thank you, sister, for informing me. I would like to see the family".

On the 17 May, I went to the intensive care unit, and asked a few nurses about how they felt:

N: "Sister, how do you feel about Selby's death?"

Sr: "I think, all of us nurses, feel he rested. He was too ill to survive. We did everything we could do. He was lucky though, to have somebody like you to care for him".

The other sister came along.

Sr: "Well, matron, your patient could have not survived. He had too many complications. His mother one time told us he had been ill for a long time at home. By the way matron, Selby had his Last Sacrament on the 16 May, in the morning. I did not get the priest on Saturday and Sunday"

The doctors came in as I spoke to sister:

1st Dr: "Sorry, matron your patient had too many complications".

2nd Dr: "Was he your relative?"

N: "No, I am doing research".

2nd Dr: "Well, I learnt from DrX, that the patient could not go to the operating theatre before seeing you. Can't you do research on this poor little soul, who looks so miserable?"

N: "No, doctor. I am doing adult patients, but who are mentally sound".

#### DEATH RITUALS PERFORMED

At the mortuary we prayed. The elderly aunt then took out the Ziphuf-mucronaea twig from the bag. She put it on the coffin, and said, Selby! Selby! We are now going home".

The other old lady explained to me, they had to call his spirit so as to take it home, to his people and ancestors. The aunt, again spoke to the spirit. "We are now getting onto the bakkie".

On asking the elderly lady, she said the aunt was to remain silent until they reach Hluhluwe. They had slaughtered a goat at home, and made Zulu beer. It had been placed in late granny's kitchen. The twig was to be placed there and the coffin in the late's bedroom. When they reach home the twig will be placed next to the meat and Zulu beer. The aunt was to say, "Selby, you are now at home. Join your ancestors. Do bring us good luck, and join the others in protecting us".

Selby's funeral service was to commence at 09h00 and burried thereafter before noon, as he was young and not married. In Zulu culture a young man is referred to as a boy if he is not married.

On return from the graveyard there were two basins at the gate - one with plain water and in the other water mixed with stomach contents, for the first washing of hands ceremony. I kept and went along with the family. We washed our hands from the second basin. Meat and dumplings were served. Men sat outside under the shade and females in the dining room on mats.

Selby's mother introduced me to everybody. They all thanked the nurses, doctors, and me for our care. I was asked to send their greetings back to the caring teams in the two wards.

On my departure at 15h00, I asked about the other death rituals to be performed. They told me the Holy Mass was to be said for the late. They were not going to shave their heads or wear the mourning cloth. The second washing of hands was to be performed on the 2 July. The washing of hands is done to cleanse them of the death pollution.

On the 2 July I joined the family, and they were very happy to see me. The mother was completely relaxed and had totally accepted the death of her son. The goat had been slaughtered and Zulu beer made. They as the family had washed hands. So, I was called to wash hands as a member of the family and I did. The priest conducted a short prayer service. This was followed by feasting on meat and dumplings.

The family was informed that it was my last visit. I thanked them for tolerating my numerous questions. They in turn thanked me, and still sent greetings to the doctors and nurses. When I did, sister exclaimed, "No, matron, Selby was indeed as your relative". We both laughed, as well as the rest of the team.

## INTRODUCTION

Mrs Khombisa X., was a sixty year old married woman. She was a mother of four children, aged 22, 16, 12 and 8. She was hospitalised on the 21st March, 1983.

## ON ADMISSION

The nurse's interview sheet indicated that she was admitted in a very ill condition. She was grossly emaciated, complaining of sharp pain in the chest, and difficulty in swallowing. She was mentally sound and independent.

The doctor's notes contained the similar information, and ended with the diagnosis of cancer of the oesophagus. Sedation was prescribed for her, and she was due for further assessment by the senior surgeon.

## FAMILY BACKGROUND

Khombisa was married and had four children, two sons and two daughters. The eldest son was working in Durban, with the father. The other three were still schooling at Melmoth. The father and the son returned home every month end, and on long weekends. She described her husband as a very loving and a responsible person.

She stayed at home and had never worked in her life. She stayed with her in-laws in the extended family. There was the grandmother, the mother, two brothers with their wives and children, and her children on the same premises.

Khombisa was illiterate, but was happy her children had been sent to school and enlightened. She and the family were not Christians.

#### RESEARCHER'S FIRST ENCOUNTER WITH THE PATIENT

At a glance, Khombisa appeared to be very emaciated, miserable, and her head sunk into the pillow. She appeared very helpless and too weak even to raise her head from the pillow. She was on intravenous therapy. I helped her to raise her head by adding another pillow. After introducing myself, she introduced herself to me.

Khombisa gave a verbal consent to be interviewed for research purposes. She refused to sign the consent, saying she trusted me. She refused the tape recorder because it would identify her and she also did not know the effects of one's voice being recorded. She was smiling and relaxed as she spoke. She then, on my request, told me her illness history.

At the end of the first interview the patient said, "Mthembu people are kind-hearted. The manner in which you have spoken to me, not in a hurry, seated, which shows respect, has impressed me. You even told me you are MaMthembu (nee Mthembu) which is very natural in our culture. We traditional people, do not understand this "Mrs". We know that "Mrs" is a White man's wife." We both laughed.

#### ILLNESS HISTORY

##### Previous Illness:

She was a strong, healthy person and just had minor ailments, like a common cold.

## Present illness:

She started losing weight gradually from 1984. She had no pain or discomfort. She then developed epigastric pain as from 1985. She went to various private doctors, and all in vain. At the same time she went to various witchdoctors. In 1986, she went to the prayer women, as well. Somebody recommended a prayer woman at Inanda, near Durban. She prayed for her and gave her an emetic. She said:

P: "Do you know what I brought up from the epigastrium? A piece of flesh! It was an "idiso" my child! Do you know "idiso"?"

N: "I know it, but can you explain how yours looked like?"

P: "It was a piece of foul smelling flesh, and when it was examined, it had maggots inside."

N: "Was it painful when you vomited it out, and did you experience any relief?"

P: "It was painful when it came out. I had some pain relief for a few weeks."

N: "Did the prayer woman give you a course of treatment?"

P: "No, she had done her part - the "idiso" was expelled. That woman was powerful!"

Khombisa went on to say the pain continued. She again went to different White private doctors. Somebody told her of a Black doctor at Esikhawini Township. She went there, in December 1987. This doctor referred her to Ngwelezana Hospital, as he said she needed hospital investigations and treatment. Khombisa went back home. The

pain grew worse. She again went to the private White doctors at Empangeni. She was treated with tablets, mixtures and injections. She feared to come to the hospital. She feared she would die.

N: "Do you think people die in the hospital, or was it your condition of illness that made you think so?"

P: "Well, one always thinks the hospital is haunted with the spirits of the dead. My condition was so bad that I felt helpless. When I looked at myself, I saw I was skin and bones."

So ultimately, Khombisa came to hospital because she could not swallow anything - even diluted porridge, she stated:- "The pain was growing worse day by day, so I had no choice, except to come to the hospital."

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The doctor informed the patient she had cancer of the oesophagus on the 25th March. The sister who was with the doctor, said the patient was shocked to hear the diagnosis.

The patient informed me on 7 April that she was worried about this cancer growth which was blocking her oesophagus. She said it was causing her a lot of pain and the dysphagia. She was asked what doctor said about her course of treatment. She said he said he was going to insert a tube to assist her to at least swallow a fluid diet. She complained of pain, constipation and feeling weak. She added that this "idliiso" had ruined her inside.

P: "I did not come to the hospital as I thought I was going to die. I felt so helpless and I was just bones and skin."

N: "When you thought you were dying, how did you feel?"

P: "I just feared the unknown future. I felt sorry for myself, my children and my husband."

On the 13th April, the patient again raised the point of dying.

P: "I am in pain, severe pain, and I think I am dying."

N: "What exactly are you feeling, to think like that?"

P: "Well, doctor said I have cancer. As you see, I am just skin and bones. I cannot eat, I am helpless, I am getting weaker and weaker, day by day."

N: "Now if you feel like that what would you like to arrange for, and what strengthens you?"

P: "My children have a responsible loving father, and a grandmother. I trust God is with me."

Khombisa was asked how she felt about doctor telling her her diagnosis. She said, "Doctor is good and honest. He told me my illness is not curable. That is honesty you would never get with a witchdoctor." I asked her how she felt about her condition being incurable. She said, "I was upset, I cried, and wished as if I could die immediately. As days went by, I felt I should stay in doctor's care, although he said I could go home. I think he has better treatment relieving my pain."

The patient always complained of pain on swallowing, even after the

insertion of the celestine tube. She focused on the tube and at times she said it was poking her inside.

There was a time, early in May, when she had severe stomatitis. She regarded it as the outcome of the "idiso". She would stretch out her arms, to show me how she had lost weight. She made me feel her collar bones, how they were protruding due to weight loss. She told me she used to be big and plump, and point at a nurse wearing a size 42 uniform. When I teased her, that was she not my size, she would laugh and say my size is a disgrace for a married woman.

#### FAMILY REACTION TO KNOWING THE PATIENT'S DIAGNOSIS

The family was met only twice during her hospitalisation. It was her mother-in-law and her daughter. The mother-in-law said it is "idiso" that doctors name cancer. She claimed it must be the scar where it had implanted itself. It had done a lot of damage inside her stomach and oesophagus.

The mother-in-law said, the reason for bringing her so late to the hospital, was to enable her to get strong injections for pain. She expressed that they had lost hope of her survival, as she was dying slowly, and all that was left of her, was skin and bones. She said, all the family was just waiting for the day of actual death.

#### PATIENT'S RELATIONSHIP WITH ALL THE CAREGIVERS

##### 3.1 Doctors:

The patient was positive to the doctor, for his honesty in telling her

about her illness and the course of treatment. I asked her:-

N: "Do you have confidence in your doctors?"

P: "Yes, nurse, the bald-headed man! It is just that he cannot speak Zulu. He listens when a patient talks, examines where you have pain, and will prescribe treatment."

The mother-in-law also said the patient was very happy with the doctors. They were kind and caring.

#### Nurses:

Khombisa always told me that the nurses were kind and caring. It was only one day when she reported that they had not put up her drip. It was at 13h10, and she said the intravenous fluids had been on her locker since 07h00. Sister's attention was drawn to this, and she put up the drip.

On 14 April, I asked her whether the nurses were doing all she expected them to do. She said, "At times - I think twice a day - a nurse comes and asks me how I feel. I tell her. She writes on my record and passes on. Now, I don't know what that is meant to do for me as a patient." She felt feeding her, bathing her, turning her, giving her treatment, was more meaningful.

#### Researcher:

A relationship of trust and confidence was established in the first encounter with the patient. She informed me of doctor's visits and

what they had said about her treatment.

Khombisa was hurt if I came when she was asleep. She would blame the injection. On 2 May she informed me, in a whispering tone, that she had stress incontinence and dysuria. She had not told anybody, as she felt it was some kind of disgrace that could be told to a close friend or a family member. The next day I visited her, she had an indwelling catheter and was very grateful.

The patient told me about the family's visits over the weekend and would tell me they were grateful about my concern. On 9 May, after a weekend, Sister saw me enter the ward at 07h15, and she said:

Dr: "Oh! Thank you for coming to see her. S' has been miserable over the weekend, but she did not say I must call you. She is going to take treatment and feeling well today."

N: "Was she feeling lonely?"

Dr: "Well, I don't know, but she likes you more than all of us. She even struggles to fight the effects of sedation, waiting to see you come."

N: "Sister, do call for me, if you see her do that."

#### CAREGIVERS SUPPORT OF FAMILY

##### Doctors:

The Doctors never met the family. The patient informed them her doctors were good, hence their praise of doctors when I met them.

Nurses:

The nurses were asked what they said or discussed with the family. They said they reassured them. When Khombisa had been wanting to go home, they did not inform them. When asked whether they discussed that Khombisa was dying, they said they did not as it was an obvious fact to them.

#### PATIENT'S FAMILY WORRIES

The patient was worried about her children, particularly the eight year old daughter. When she told her illness history, she said she was not keen on being admitted because of her concern for the children. She said, "Even if the granny is there, they still need me as a mother."

Khombisa told me that her husband was a responsible person and would keep an eye on her children. The husband and working son visited her over the Easter weekend. On the 10th April, she told me she felt she was dying slowly. She was worried that she was not going to see her first son's baby. She said:-

P: "I have not seen my grandson, and I think I never will."

N: "Congratulations on being a grandmother. Is it not possible that they bring the baby?"

P: "No, nurse, we are traditional people. The mother is still polluted, and cannot travel yet."

N: "But then, tell me whom do they say it resembles?"

P: "Who else - the grandfather!"

N: "Khombisa, do you see God loves you. Although ill, there is good news for you!"

P: "Yes, nurse, I shall die happily!" (She laughed and we shook hands).

Khombisa's family visited her on Monday 2 May, but she told me they were in a hurry to wait for me. On 5 May, she cried when I was just talking to her. She told me she was missing the family togetherness. I organised ambulant patients to keep her company when she was awake, to exchange with nurses. She never complained or cried until her death on the 12th May.

#### FAMILY SUPPORT TO PATIENT

The patient's family visited her at least once a week. The husband and the working son came three times during her illness. Over the Easter weekend, the husband came on Saturday, Sunday and Monday on his way back to Durban. Khombisa spoke positively of them all. They brought her mass, orange juice, and left her money. She always knew when they were coming, and they would come.

They reassured her of the care of her children. One child came along with a family member. They never discussed dying with the patient. When they left, they assured her that the ancestors were there with her to protect her.

## INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

The patient informed me that she was not a christian. I asked her on 13 April:-

N: "What strengthens you at such a time?"

P: "I trust that God will be with me."

N: "But you told me you were not a christian, and believed in ancestors?"

P: "Yes, nurse, I like to be a christian."

N: "Does it mean you want to be baptised?"

P: "Yes, I do. But let me think it out, because my family do not like that I be baptised."

N: "Can I arrange that a pastor comes here and discuss this with you?"

P: "Just wait, nurse. I shall tell you, when he should come."

N: "Can we pray together, then?"

P: "Yes, nurse."

Khombisa did pray, asking God to be with her at such a terrible time of her life. She prayed that God's will be done, so that she can come to Him, and enjoy eternal life. After the prayer, Khombisa informed me that her family at times went to the Zionist Church, to attend the service and revival meetings.

On the 3rd May, when I left Khombisa's ward at 06h45, I was approached by a general assistant.

G/A: "Matron, I have been longing to see you. I have seen you several times visiting Khombisa. You see, mama, as we clean the ward we do see the very ill patients. As an adult, I do speak to those who seem to be dying, about preparing for their journey to the next world."

N: "That is very good. I am also assisting her and have spoken about baptism. She seems agreeable. I am just waiting on her to say I must call the pastor."

G/A: "O! Mama, I am happy we are both trying to win a soul for the Lord. You are really doing a good job. Her visitors come once a week or fortnight."

N: "Thank you. So, when I am off, you shall visit and pray with her."

On the 9th May, Khombisa told me she wanted to be baptised, but was scared of her family. We, however, on 11 May concluded that I would come with the pastor on 14 May. She said, "O! Nurse, you do care for my soul, God bless you."

On Thursday 12 May (Ascension Day) at 08h15, Khombisa died. I was sore in my heart about the death prior to baptism. It was only on the 20th May, that I met this general assistant, and I asked her:-

N: "Were you on duty, when Khombisa died?"

G/A: "Yes, mama. When we came on duty she was gasping. I overheard the night nurses giving the report saying the patient wanted you, but they were afraid to call you. The day sister said, they should have called you, as she was your case. The night sister said she had not been given that report, and she just thought the patient was making a fuss. So, mama, I inwardly felt she wanted to be baptised. So, I kept on watching and listening whether there was anybody phoning you, and nothing was done. So, mama, I got water in a small bowl. I went behind the screen, and I asked her whether I could baptise her. She nodded as she was on oxygen. I prepared and baptised her. She responded and said, "Amen."

N: "O! I am pleased! God be praised! I have been very upset since Saturday afternoon, when I phoned to say I would be coming with the pastor, to be told she had died on 12 May."

G/A: "I did think of you that you will be hurt, if I did not baptise her. I am terribly sorry for you that she died, you were so attached to each other. Please, matron, seeing the nurses did not tell you the patient wanted you, please do not say anything about what I have told you, otherwise I will be victimised."

N: "No, I shall not say anything. But I am very grateful for your spiritual concern of patients."

I made it a point to talk to all nurses that were on duty on the nights of 11 May and 12 May, to find out how Khombisa died. It was just one staff nurse, who confirmed the general assistant's report.

S/N: "O! Mama, you never know God's way. We all feel sorry for you.

I understand that in the evening of 11 May, the patient wanted you; but sister was afraid to phone you. I am now blaming myself that I did not speak behind sister, to ask switchboard to phone you. I think there was something she wanted you for or to say to you."

N: "Were you on duty when she died?"

S/N: "Yes. When we came on duty she was gasping. She died peacefully, and we did not worry her by active resuscitation."

N: "Thank you, staff nurse."

#### CAREGIVERS' ATTITUDE IN INFORMING PATIENT ABOUT DIAGNOSIS

The doctors and the researcher were positive about the patient being informed.

The nurses were all negative to the patient being told about the diagnosis. The following were the remarks they made at the various times, of the patient's illness:-

N/A: "These doctors are very funny. They simply tell the patient, and our people now know that cancer is incurable."

N: "Why do you think they should not tell the patient?"

N/A: "It should be terrible to know you are dying."

On another occasion sister said:-

S: "Yes, doctor told her. As for these doctors, they simply tell

the patient snatching news!"

N: "Why do you think telling a person the diagnosis is snatching?"

Sr: "O! Matron, to know you are going to die should be terrible."

#### DISCUSSING DYING WITH PATIENT

The doctor informed the patient her diagnosis and that it was incurable. The nurses feared discussing dying with the patient. The nursing assistant who said doctors are funny in informing patients about the diagnosis, was asked:

N: "How do you think we should care for the patient who knows she is dying?"

N/A: "I think we should pray with the patients."

Sister who was present when the patient was told her diagnosis, said the patient was emotionally disturbed.

N: "How did you help the patient?"

Sr: "I did not say anything, as I simply lacked the words to say or comfort the patient. I felt pity for her. On the other hand, I got fed up with this doctor."

On the 7th April, sister informed me that the patient had a Livingstone tube inserted, and that doctor said her cancer had secondaries.

N: "Are you discussing the diagnosis and prognosis with the patient?"

Sr: "No, matron, I cannot do that! My duty as a nurse is to reassure the patient. I would depress and upset the patient."

The third year diploma student said: "I am afraid to discuss such a thing with the patient, even the sisters are afraid."

The nursing assistant said:-

N/A: "No, I did not discuss that, but one day she asked me whether I thought she was dying or was going to survive."

N: "What did you say?"

N/A: "I said I did not know. It is God only who knows whom He is going to call."

N: "What did the patient say?"

N/A: "She said, I was correct."

Khombisa was asked on 14 April, whether the nurses discussed with her about her condition.

P: "No, they just stand at the bottom of my bed, and speak English, as if they are Whites, and pass on."

N: "Well, mama, when they exchange shifts they have to give each other the report about each and every patient. Now, they are taught in English, and have been taught to give the report about the patient's condition in English. There are some of the details in the explanation of the disease, that are difficult to say in Zulu - in fact, we have no exact word."

P: "I see - but also all these funny diseases we die from came with the Whites!" (She laughed aloud and so did I).

On the 18th April, sister informed me:-

Sr: "Your patient is very ill. She is in severe pain, but the sedation is helping her. I think she is dying."

N: "Are you discussing her feelings about dying?"

Sr: "I did not, and she does not say anything. I think she realises she is dying. So, we as nurses cannot aggravate her misery."

As I spoke to sister, the doctor joined us.

Dr: "Your patient is now catering to her death. I told her she has cancer. She just needs supportive care."

N: "Can doctor explain to sister what he means about supportive care?"

Dr: "I expect a nurse to be constantly with the patient, and discuss with her the impending death."

Sr: "O! Doctor! O! No, what? That is difficult! Can you do it yourself?"

Dr: "You see, matron - I told you last year that my patients die a lonely death. (Doctor shook his head, and walked away, saying) "Matron, you have a duty to do - teach your nurses."

## FAMILY REACTION TO PATIENT'S DEATH

The family was met at the mortuary on the 17th May, and they had accepted death.

N: "We as nurses are sorry that she died."

M: "Yes, my child, but she was already dead alive. You have never seen such a "live skeleton". She was terrible to look at. We lost hope long ago."

R: "Yes, nurse, even at work I was awaiting the death news. When I received the telegram, I knew its contents, even before I opened it. We have all been waiting for her actual day of death."

## CARERS' REACTION TO PATIENT'S DEATH

The doctor, nurses and the researcher accepted death as a reality. The doctor had even written on the patient's chart that no doctor should be called for resuscitation. The nurse, when asked to, supported this opinion, and indeed just kept the patient on oxygen when she was gasping.

The doctor and the nurses pitied the researcher for the patient's death. Also the general assistant that baptised the patient at death, pitied me.

## DEATH RITUALS PERFORMED

Khombisa was buried at the Ngwelezana cemetery, on 17 May. At the mortuary we said a prayer. The elderly uncle took out a ziphuf-muchronaa twig from the bag. He put it on the coffin, and said,

"Makoti, it is your uncle calling you, let us go home now. We are going to put your body to rest, and then go home." So, we lifted the coffin onto the bakkie. He spoke again, "Makoti, we are getting onto the bakkie." He kept silent.

At the graveside we sang hymns, and the Zionist priest conducted the service. He read the Bible, preached and talked to the ancestors as well. When we finished, the elderly uncle put the twig on the grave, and said, "Makoti, we have put your body to rest and now we are going home."

I was not able to go with them. I asked the husband what was to be done at home. He said, they had slaughtered a goat and made Zulu beer. This had been placed in the granny's hut. The twig was to be placed there, and Khombisa's spirit would be told to join the ancestors, and be asked to be a good protecting ancestor. He said, at the gate entrance there will be plain water, and water to which will be added stomach contents. That was to be the first washing of hands ceremony. The children and him were to have their heads shaved. He, as the husband, was to go via the river to bath, before going home. All the extended family members were to wear a mourning sign and all children a string around their necks.

On 2 July, I joined the family for the second washing of hands ceremony. When I arrived at 14h00, I was told that they had slaughtered a goat, and the family had washed their hands, with water to which was added the stomach contents. So, one of the family grannies called me, and had to wash my hands. She said, I am as good

as a family member. I asked whether there was any other ritual that had been performed. She said everybody - children and adults - had removed the mourning strings and signs. These had been burnt outside the fence by one of the grannies. She said, the reason for performing the second washing of hands, so soon, was to avoid the recurrence pollution. This type of disease, that is incurable, was viewed with great suspicion by the family, that it would recur.

Before feasting, there was a prayer conducted by the Zionist pastor. I told him and the husband before starting that Khombisa was baptised. They were both very excited. During the prayer which was conducted in both christian and traditional manner, it was announced Khombisa was baptised. Everybody was happy and said, 'Hallelujah.'

After the prayer, men went into their hut and so did the women. The next was served with dumplings. I thanked everybody for tolerating my numerous questions, and they in turn thanked me.

They were particularly happy about her having been baptised before her death. They asked me to greet and thank the doctors and nurses that cared for her. A special word of thanks was sent to the general assistant that baptised her.

## INTRODUCTION

Mr Mbongeni X was a 45 year old single male. He was a father of three children. He was illiterate and did not know the ages of his children, but from our discussion, it seemed they were between the ages of sixteen and ten years. He was from the KwaMthethwa area in the Empangeni district. He was hospitalised on 2 May, 1988.

## ON ADMISSION

Mbongeni was very ill when he was admitted. He had gross ascites, gross oedema of the lower limbs and was very dyspnoeic. He was in such respiratory distress that he could not give a history of his illness. He gave this on the third day.

He complained of frequency of micturition, constipation, nausea and oedema of both legs for two weeks. He had dental caries, jaundice and his clinical picture was that of an alcoholic. He was unable to stand. He was well orientated, alert and responsive. He was totally dependent. The patient admitted being an alcoholic.

The doctor diagnosed the patient as hepatic failure, gross ascites and jaundice. He prescribed a low protein diet, an antibiotic and a diuretic and said he was terminal.

## FAMILY BACKGROUND

The patient had three children; the fourth had died. All the children were born of different mothers and stayed with their mothers.

At his home he stayed with his mother, grandmother, sister and a brother who was married. Mbongeni's father was alive, but had deserted them and was staying somewhere with a mistress.

Mbongeni had been working on the sugar cane fields and lived at the compound most of the time. He had returned home when he was ill. His family was illiterate, but his brother's children were schooling. They were not Christians. The patient expected his brother's wife and his sister to visit him in hospital. Mbongeni said he had a mistress who was working at the sugar cane field, but did not expect her to visit him.

#### RESEARCHER'S FIRST ENCOUNTER WITH PATIENT

I met Mbongeni on 5 May at 06h20. He appeared anxious and I noticed the grossly distended abdomen and the dyspnoea. He was propped up against the backrest and pillows. He was nursed in a cotbed. As I came closer, I noticed the sweating and that he was jaundiced.

When I finished introducing myself, he asked me where my home was. When I said at Kwamthethwa area, he was happy and said he knew my father-in-law. "So you are our 'makoti' who cares for us!" We both laughed and he shook my hand. He asked me to open the cotbed, saying, "Makoti, these nurses are treating me like a child! Who said I am going to fall?" So, I opened it. (I had read his chart and it said that he was disorientated during the night of 3 May).

The patient consented to being interviewed for research purposes, but refused to sign the consent. He said, "I trust you, makoti." He

refused the tape recorder. He feared that the ancestors would view it badly if his voice was talking after his death.

The patient appeared to be a pleasant, soft-spoken person. He asked me whether I would like to meet his family, as he felt they should see me, as I was makoti. He asked me why I was wearing a navy-blue dress. I told him I was a nursing administrator. So, we discussed his family background as well. The patient was happy I was to see him regularly, saying, "It is good that there are nurses who are still so respectful, and even take their time and sit down to talk to a patient."

#### ILLNESS HISTORY

##### Previous Illness:

Mbongeni claimed to have been well until the present illness which started in mid-1987. He said, "I was healthy, strong and enjoyed my alcohol."

##### Present Illness:

The patient said, "I do not know whether you know Zulu illness?" I nodded. He then continued to say he was bewitched by an induna who hated him. He sprinkled bad medicine next to his locker at the compound. He walked over the muthi and the disease went up his legs, causing them to swell up. The illness further went up his back and to the abdomen, causing it to be so distended. He wanted me to look at and examine his legs and back, although I was makoti, who should respect the exposure of the in-laws bodies. He added, "Do look

because although I am like your brother-in-law, but you are on duty." So, I did lift the bedclothes and felt his legs, back and abdomen. He jokingly said, "Have you seen a man with such a big abdomen. You can think its a twin pregnancy." We both laughed.

Mbongeni was asked whether he had sought any form of treatment. He said that he had been to various witchdoctors and had spent about R800,00 in all. He also consulted a number of prayer women, who confirmed he had been bewitched. He then decided to come to the hospital on 2 May, as he had lost confidence in the witchdoctors.

N: "Didn't you think of trying doctor first?"

P: "I could not have just come to the doctor first, with an OBVIOUS Zulu disease. Seeing Zulu treatment has failed, then I have come to try the doctor."

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was informed by the doctor that he had liver failure and it was so advanced that it would not be curable. The male senior student nurse who interpreted for the doctor, said the patient nearly collapsed, but collected himself, as a man should.

The patient informed me that there was no hope for him and that doctor had told him his liver is damaged. He was grateful that he had been told. He just kept on feeling his abdomen and saying this bewitchment had messed up his life. He preferred dying in hospital, as the doctors and nurses showed concern.

During a conversation with the patient, he said:-

P: "I am lucky that I can still talk and thank them, (the nurses) because I don't think I will live long."

N: Why do you think so?"

P: "I am just feeling weak and I have been ill for so long. Even my body looks thin, no more like me in those days. Death is after me like a monster. I am just dying."

N: "How do you feel, exactly, when you say you are dying?"

P: "It is a depressing, frustrating feeling of helplessness. It makes me anxious, and I feel as if my whole body is stopping to function. It brings to my mind a flood of miserable thoughts, particularly about my children." (His voice was shaky).

N: "I understand. When you feel like that, what do you expect us to do for you, as we cannot see how you feel?"

P: It is better when you talk to me and I can discuss this. I then feel better when I have talked about it. There is nothing else you can do because I am aware I am dying."

N: "Do you like to have somebody to talk to regularly?"

P: "Yes, makoti, because at times I simply fear the idea that I am dying."

N: "I shall do something for you."

#### FAMILY REACTION TO KNOWING PATIENT'S DIAGNOSIS

The family was informed by the patient that he had incurable liver

failure. They were not surprised that his condition was not curable. They said that it is normal for doctors not being able to treat Zulu disease. He had been bewitched. They felt that bad medicine had settled in the liver and destroyed it.

They felt he was very ill and had been ill for some time. The sister told me they only knew he was very ill in November 1997, at the farm compound. He had not been returning home and had not been supporting people at home financially. So, when he was ill, he kept it a secret. He had been enjoying his money with his mistress. This mistress deserted him when he became very ill. The mistress was also responsible for the bewitchment. She was an evil woman. They had fetched Mbongeni from the farm, sent him to the witchdoctor and the ascites subsided. He had gone back to work and to this mistress, very much against the family's wishes. So, the mistress got him again and bewitched him. And again it was they who fetched him. She said that Mbongeni was just a heavy drinker and was useless to the family. The two women sounded angry as they told this story.

This long story ended by the sister saying:-

Sr: "Well, nurse, it is just that in Zulu culture, we say 'There is no refuse bin for a human being', which means there is no human being who is worthless.

N: "Wonderful! That is a proper summing up of a sad and irritating matter! Then, I know we are both supporting him. (They nodded and we all laughed!). Tell me, is it the first time he is admitted?"

Sr: "No, in November and December we went up and down to the witchdoctors. In January we sent him to Hlabisa Hospital. He was given treatment in hospital for two weeks and discharged with a referral letter to Ngwelezana Hospital. When he was discharged he did not take treatment, he only drank his liquor and did not come here. That is why we seem agitated by his condition. He allowed this and he is responsible for it."

N: "Did you not urge him to come to hospital?"

Sr: "He was negative to hospitalisation. Even the Hlabisa admission. He was visiting friends and he started vomiting, so they sent him to the hospital. So, in February, we sent him to a number of private doctors, I think three, and they all recommended hospitalisation. So, he ultimately agreed to come just this month. So, how can we expect miracles from the doctors?"

#### PATIENT'S RELATIONSHIP WITH CAREGIVERS

Doctors:

The patient was positive that doctor told him about the state of his health. He was very grateful that the doctor who tried and failed "tapping him", (doing a paracentesis abdominus), told him he was calling a senior doctor. The fact that the senior doctor was a Black, further amused him. When I came to see him, he related to me what had happened and ended up by asking:-

P: "Makoti, the Black doctor was teaching the White doctor - is this normal practice in this hospital?"

N: "Yes, and in other hospitals too - a senior teaches the junior. They pass the same examination to be doctors."

P: "It is the first time to me to see a Black doctor in hospital. But things have changed in this country! I am pleased. The huge abdomen is flat or I have delivered!" (We both laughed).

N: "Where are the twins, then!" (We laughed).

#### Nurses:

The patient spoke very positively of nurses. The day he complained of the cotbed, he also disliked the backrest, but when it was explained to him why he must lie in that position, he was positive. When asked how he showed his gratitude, he said he verbalised it each time they assisted him.

#### Researcher:

In the very first encounter the patient accepted me as a nurse and a person from his own area. He informed me of his illness history and family background. I think it was out of respect for a "makoti" that he left out the other illness history given by the two sisters. What he left out is what is traditionally referred to as "the lice of a man" (a man's disgrace; in Zulu "icintwala zendoda"). It is facts left out deliberately to save a man's image.

#### CAREGIVERS' SUPPORT OF FAMILY

##### Doctors:

The family heard of the good doctors from the patient. They in turn, spoke positively about the doctors.

Nurses:

The nurses met the family each time they visited the patient. When Sister-in-charge was asked what she discussed with the family, she said, "I blamed them for bringing the patient to the hospital so late." A staff nurse, nursing assistant and a student nurse said they just told them to trust in God and pray for the patient.

On the 11th May, Mbongeni was critically ill and the family came. Sister told me she had spoken to them. She said they should pray as she saw they looked very disturbed.

Researcher:

The first encounter with the family was when they gave his history. We discussed their feelings as the patient's condition further deteriorated. They trusted that I would keep an eye as I was always at work. I told them I was off on weekends, so we agreed on one of them visiting the patient on Saturday.

The family members were asked what strengthened them, they said they believed that their ancestors were with them and with the very ill brother. They believed the ancestors would meet him, so that he is relieved from the pain and suffering.

#### PATIENT'S FAMILY WORRIES

The patient worried about his three children. He expressed this the day doctor had told him about his diagnosis. He also expressed his worry about the children a day before his death, to his sister-in-law.

He actually said, "As you see me, I am finished. Please keep an eye on my children. If their mothers bring them home, do accept them." The sister-in-law promised him to do that, and he was happy.

He told me he was worried that the children were young and scattered all over. He was reassured that a child grows better under the care of the mother. He accepted that.

#### FAMILY SUPPORT TO PATIENT

The family came regularly twice a week to see the patient. The patient appreciated that. The day they talked to me about his illness history, it was obvious they were determined to support him during this troubled time. Their willingness to visit him, spending their money when he had not been supporting them at home, is indeed an expression of their love for him. The money that was spent on the witchdoctor was actually from the family. Mbongeni told me about this a day before he died.

The family did not discuss the patient's death fears and feelings. They came to me to discuss their feelings and their observations of signs of the impending death.

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

The patient told me he believed there was a Creator of heaven, earth, humans and all living and non-living things. He believed his ancestors were alive, as the spirit did not die. He believed that his ancestors were with him even in hospital. As he felt he was dying, he said they were going to meet him and take him to join them.

## CAREGIVERS ATTITUDE IN INFORMING PATIENT OF DIAGNOSIS

### Doctors:

Doctors freely discussed the diagnosis with the patient and that his condition was incurable.

### Nurses:

All the nurses in Mbongeni's ward thought it was not correct to inform the patient about his diagnosis. The finalist student nurse said, "I do not think it is good to tell the patient. This patient nearly collapsed." A first year student nurse felt it shortens the patient's life. All the Sisters said it is not proper to inform the patient, as he tends to worry too much. One sister said it just made nursing the patient difficult and the doctor who has caused such a situation only comes for a ward round and goes away.

### Researcher:

I was positive about the patient being told. I assisted the patient to express his feelings and fears, to discuss them with him. The patient found in me a sister in whom he could confide.

## DISCUSSING DYING WITH THE PATIENT

### Doctor:

The doctor only informed the patient about his bad prognosis. The patient fully understood that doctor meant he was going to die.

## Nurses:

The nurses were asked at different times whether they discussed dying with the patient. The following were some of their responses:-

(i) Stud/N: "It was unfortunate for me to have to interpret that for the patient. The patient nearly collapsed. He just had to collect himself, as a man."

N: "Did you go back to reassure the patient after the doctor's round?"

Stud/N: "Oh no, matron. It would destroy him. I think it is not good that doctors tell the patients about their diagnosis, but I think in all the wards they tell them."

(ii) Sr: "O. No, matron, I just reassure the patient as a nurse. It is doctor's duty to do that."

(iii) C/P/N: "It is very difficult to discuss the impending death. I suppose it should be done, but I think it needs special training."

## Family:

The patient expressed his death fears to the family, but they did not respond to such a conversation. They came to me to tell me what the patient said and quoted such expressions as, "I am finished; I am so helpless; I don't think I will make it."

#### FAMILY REACTION TO DEATH OF PATIENT

The family had expected the death of the patient - as already stated. They felt they had done their best in helping the patient - sending him to private doctors, to the witchdoctors, and when all that had failed, had brought him to the hospital so that these doctors could also try to help.

When the patient ultimately died, they accepted the death quietly.

#### CAREGIVERS REACTION TO PATIENT'S DEATH

The doctors, nurses and myself accepted the death of the patient. All felt they had done everything possible for the patient. The nurses again expressed pity towards me on the death of the patient.

#### DEATH RITUALS PERFORMED

The family was met at the mortuary on 16 May. The grandfather had brought the ziphuf-mucronsea twig for taking the spirit home. When the coffin was lifted from the mortuary, the grandfather said, "Mbongeni, my grandson, let us go home. Mbongeni, we are getting onto the bakkie", then put the twig on the coffin. He then kept silent until we reached the Ngwalezana cemetery.

The Zionist pastor conducted the funeral service. He prayed and called upon the angels to meet Mbongeni. He called upon the ancestors to receive him in their underground world. When all was finished at the cemetery, the old man put the twig on the grave and said, "Mbongeni my grandson, we have put your body to rest here. I am going

home with you now. Let us go." He then kept quiet. When they reached the bakkie he said, "Mbongeni, we are getting onto this bakkie, to take us home."

I asked the older aunt what else was to be done at home. She told me they had slaughtered a goat and made Zulu beer. When they reached home the twig would be placed in the grandmother's hut, where there was meat and beer. I asked why in granny's hut. She said, the ancestors are closer to elderly people. So, in every home the old people's hut is considered as the place where the ancestors reside.

The old lady further informed me that when they reached home, they would wash hands at the gate entrance, with water to which stomach contents had been added. The hands are washed to cleanse the people from the death pollution. There would also be clear water, in case there were some people who believed that performing customs meant worshipping ancestors. She said they would then feast on meat and dumplings, and then the people/neighbours would disperse.

I asked the old lady whether there would be any other rituals to be performed. She said they would perform the second washing of hands ceremony on 7 July. I informed her that I would join them. She was pleased and said I was indeed a family member. I asked her about the hair cutting and she said they were going to shave the heads of the children and male family members, outside the fence. They were not to wear the mourning sign, as that was done by Christians.

On the 7th July, I joined the family at 11h45. I was warmly welcomed.

I was introduced to the rest of the extended family and the neighbours. The same Zionist priest who conducted the funeral service, conducted a short prayer. The grandfather spoke to the ancestors. The men and women separated into different rondavels. Meat and dumplings were served.

When I was about to go, I asked why the funeral and the second washing of hands were performed before 14h00. The old lady said it was because Mbongeni had not been married. He was as good as a boy. I asked about the rituals performed that day. She said they had washed hands in the early morning with water to which had been added stomach contents.

The family was thanked for their participation in answering all my questions. They in turn thanked me for my care and concern. I was also asked to greet and thank the doctors and nurses that cared for Mbongeni.

CASE NO. 9 : MRS GEZEPHI X.

## INTRODUCTION

Gezephi X was a sixty year old mother of six children; a son and five daughters. One of her daughters - the first born - was an illegitimate child who had been born before marriage to the father to the five children. Gezephi was from the Maphumulo district. She was hospitalised on 3 May, 1988.

## ON ADMISSION

Mrs Gezephi X was very ill on admission. She was alert, responsive and well orientated. She complained of difficulty in swallowing, and loss of weight. She had no appetite. She complained of a persistent cough.

The nurses' interview sheet indicated that the patient was aware of her diagnosis which was cancer of the oesophagus. She was a re-admission. The doctor's notes also indicated the same diagnosis.

## FAMILY BACKGROUND

The patient was widowed. Her husband died in 1981. Her eldest daughter was married and lived at KwaMbonambi. Her husband was a responsible person and the couple were concerned about Gezephi's illness and cared for her.

Gezephi said her son was the first born in her marriage and described him as a useless thing. He was married and worked somewhere in Durban, but did not send money or visit her. His wife also never visited home. All three Gezephi's daughters had illegitimate children. She cared for the children of two of them while their mothers were at work at Empangeni. One daughter had gone back to school in the Richards Bay area, and she and her child stayed with her married sister at KwaMbonambi. Her two working daughters had taken their children when she was admitted.

Gezephi and her family were Christians. They belonged to the Lutheran Church. Gezephi was illiterate.

#### RESEARCHER'S FIRST ENCOUNTER WITH PATIENT

She was found sitting on top of the bedclothes on 23 May at 12h30. She was leaning on a backrest. She looked very emaciated and miserable. She spoke politely with a hoarse voice.

She consented to being interviewed for research purposes. She queried why she should sign the consent, because all the nurses and doctors here at Ngwelezana and King Edward Hospital have asked her many questions but never asked her to sign consent. She refused the tape recorder, as it would identify her.

It was during this encounter that she gave me the family background. She questioned me about my place of birth, religion, my mother's surname, my grandmother's surname. It looked as if she wanted to find a common factor or relationship between the two of us. The common factor was our religion, and this pleased her a lot. She got further excited when I informed her that I did my teacher training at Umpumulo in the 50's; before I took up nursing, since this was where her induna/home area was. I told her it was where I taught Sunday School, when I was a student teacher. The area was called Nothweni. She laughed and shook my hand.

#### ILLNESS HISTORY

##### Previous Illness:

She claimed she had never been ill as such, except for minor colds. She told me she used to be a plump, round lady, and took a size 42 dress. She now wears a 36.

##### Present Illness:

Gezephi started losing weight for no apparent reason, in late 1985. She was not feeling any pain or discomfort. She was eating normally.

At the beginning of 1987, she had epigastric discomfort. She had a feeling of fullness in the stomach, as if something was coming up the oesophagus. She thought she had round worms and was perhaps, going to vomit them out. However, she never vomited.

I asked her what did she think caused this and whether she sought any form of treatment. Gezepi said she wondered whether I knew Zulu illnesses. I said I did. She then said that it was an "idliso". She told me that while she was getting a pension, she had not been solely dependent on it. She ploughed the fields, particularly for cash crops, that are harvested throughout the year, for a regular income. They earned her a lot of money. "So, the enemy was not pleased with that. So, at these parties at times plates are dished out and come prepared and set up with the "idliso", if you are the wanted person."

N: "In your case, how did the "idliso" work?"

P: "You see, as I kept on feeling there is something that wants to come up, it was the implanted "idliso"."

N: "Did you try to get treatment, to detach and bring it up?"

P: "Yes, my child, I went to the witchdoctors and prayer women. They gave me emetics, but it did not come out. but I think some pieces of it came out, as I had a bit of relief."

N: "So, how did you come to the hospital?"

P: "I went to three private doctors, who treated me with injections and mixtures here at Empangeni - all in vain. I ultimately went to see a Black doctor at Ngwelezana Township. He told me that I had to come to hospital, and he did not even make me pay."

The patient was confused with the dates. Her case sheet indicated that she had been admitted in January 1988 and March 1988. In March she had a Livingstone tube inserted. She had been re-admitted on 3 May.

PATIENT'S KNOWLEDGE OF DIAGNOSIS

The patient was asked whether she knew her diagnosis during the third interview, on 30 May. the patient was restless and she claimed to be choking. She said, "I am very ill. It is just here in the throat. It is choking me." She was vomiting on and off, and salivating a lot. I assisted her with the receiver and gave her a mouthwash. I massaged her back as she eased off the attack.

P: "How did you know where to rub?"

N: "I saw you bend forward. (She smiled). Mama, tell me, do you know your diagnosis?"

P: "Yes, my child. Doctor said I have an incurable growth in the oesophagus. He inserted a tube."

Gezephi had an attack of coughing, salivating, and became restless. She was pointing at her throat. She cried out saying:-

P: "O! Lord, take me. O! Jesus, help me. Lord take me, I am suffering. O! St. Mary, pray for me!"

Again I helped her. When she settled down, she said:-

P: "Don't be surprised when I am calling for St. Mary, my mother was a Catholic and used to pray her St. Mary's! But you know my child, it is better to die than to suffer like this."

During the subsequent conversation, it seemed to me that her knowledge that she had a tube in the oesophagus, made her focus on it. In fact, it seemed she was afraid as if it would block her breathing. So, I brought a clear diagram of oesophagus leading to the stomach, and the trachea to the lungs. It was explained that it is not possible that the tube chokes her breathing. She smiled and her focus on the tube was greatly reduced.

As from the 3rd June, the patient wanted to go and die at home. She told me to tell her children to take her home and perform the slaughtering ceremony. There was a nursing assistant in her ward who knew her elder daughter, who only came in the evening. I gave her the message for the daughter. She said, "I will tell her, matron, but she earns so little. Her son, who should be doing that, has very little concern for his mother." She, however, was persuaded to plead with the daughter to come and see the patient.

During the night of the 2nd June the patient removed the drip. She refused an injection, saying she wanted to be left alone and die peacefully. As the pain grew worse, she ultimately accepted the sedation at 02h00. She then slept well, during the early hours of the morning.

The patient was disorientated on and off between 2 June and 22 June when she died.

#### FAMILY REACTION TO KNOWING PATIENT'S DIAGNOSIS

I met the patient's second daughter on the 30th May. She knew the mother had cancer of the oesophagus, and that she had a permanent tube in situ to enable her to be fed. She, however, complained that the tube was choking the mother. She said the mother feels where the tube starts and ends. The tube also forced the mother to sleep in a sitting position.

The same diagram to indicate the trachea and oesophagus was used to explain the anatomy to her, and she was relieved of her anxiety. She told me that there was actually nothing left of her mother as she was slowly dying. She complained of the irresponsible brother. She felt it would only be the girls who would bury the mother, and yet it is the responsibility of the son.

I met the eldest, married daughter on the 10th June. She gave the same information as her sister. She praised her husband's concern highly, and felt at least the mother had a hope that there was somebody to bury her. She felt the mother had suffered enough pain and that it would be better if the Lord released her by taking her soul.

The youngest daughter I met on 14 June. She was very miserable and felt the mother was really dying. She cried, and was comforted.

#### PATIENT'S RERELATIONSHIP WITH CAREGIVERS

##### Doctors:

The patient was happy with all the doctor's efforts. The tube she said, was uncomfortable, but she felt she would have died even earlier without it. She was happy that doctors can tell a person what is wrong, what they can do, and what to expect.

##### Nurses:

The patient spoke very positively about the nurses. She told me that at times she pulled out her drip, but they never held a grudge for her. She said that they were respectful. The patient was particularly pleased, and even marvelled at the care, concern and respect of the male registered nurse. She asked me, "Where do you get such good respectful sons? I wish my son was like this!".

##### Researcher:

I established a firm relationship with the patient on the first encounter, as already stated. The patient called for me each time she felt she was dying. She entrusted her death messages for the family to me. The patient told me when she feared being alone, and discussed her feelings about dying.

#### CAREGIVERS' SUPPORT OF FAMILY

##### Doctors:

The family did not meet the doctor but heard from the patient that the doctors are good and kind to her.

## Nurses:

The patient said the nurses were kind to her children. The family reported positively about the nurses. The nurses reassured them that the patient would be better. They did not discuss the patient's fears. The message about the slaughtering ceremony was relayed to the family by a nursing assistant.

## Researcher:

The illness history and the choking tube affair was discussed and explained to the family. The slaughtering ceremony (and its meaning) was discussed with the family. The married daughter was asked what strengthened them at that difficult time. She said it was prayer and the support of family and Christian friends. So, we did pray before they left. The patient's fears and wishes were discussed. We discussed that the correct procedure is that the son should slaughter. If the daughter slaughtered, it would not be acceptable to the ancestors. This was discussed also with the old lady, and she accepted that the daughter was to contact the brother.

## PATIENT'S FAMILY WORRIES

In the family background, the worry of the patient's son has been indicated. On the 2nd June when the patient gave me death messages, she said the son must be told to look after his sisters. The joy the patient had on 14 June when the son had phoned to enquire about her condition, was great.

The patient worried about her youngest daughter who was 17 years old. She wished she had got married. She referred to her as the "little one." She also said that her son had married a useless woman, who did not urge her husband to visit home. She said, "Then, how can I hope that she takes care of the little one!" She smiled when I said "But God gave you a responsible son-in-law." She then said, "In other words, you are saying I must forgive and forget!" (She smiled) and I said, "That is exactly what I mean."

In the very first interview the patient also complained about the heavy October rains that damaged her wattle and mud house. I asked her who had remained home. She said there was nobody. We discussed this, and resolved writing to her cousin at Mapumulo, to keep an eye on the property.

#### FAMILY SUPPORT TO PATIENT

The married daughter and her husband were the main supporters of the patient, in that they took full responsibility for ensuring she received medical treatment. The patient also mentioned that they paid for the witchdoctors who tried to treat her. The other two daughters earned very little but did all they could to support her and their children. The married daughter also provided money for the "little one" to visit her.

The Lutheran Christian friends/prayer women came on Thursdays to pray for her. She always told me that this elevated her spirit, and it strengthened her faith in God. She could not sing out, but she felt the joy of the tune and words of her favourite hymns, she asked them to sing.

#### INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

On the second interview when she told me about being bewitched, Gezephi said, "Despite all what the evil person did to me, I hope God will heal me up. I do not hate anybody. Even this unknown person who bewitched me. Even my son who has deserted me, I do not hate him. I leave it all to God, our Creator. I shall await his mercy, for the good or the worse."

The day she told me about her Christian friends who come to see her every Thursday, she said, "God is good. You know, I have been thinking that God has sent you, and He is a good God. You ask Him privately at your prayer spot and He answers you openly. Who does not see you were God sent?"

N: "What do you consider the best of my care for you?".

P: "I am no longer lonely - I know there is somebody who is going to come and see me every day. Secondly, I have somebody to confide in, a mature person. You know when you feel afraid, you fear to tell the next person, but you have offered to listen to everything that worries me."

N: "I am happy to hear that."

Gezephi called upon God when she felt she was dying on 30 May. She even remembered the mother's prayer to St. Mary. She maintained that I was sent by God even on the day of her death. She kept on praying until she took the last gasp.

#### CAREGIVERS ATTITUDE IN INFORMING PATIENT ABOUT DIAGNOSIS

##### Doctors:

They were positive about informing the patient, and coping with her reactions to death.

##### Nurses:

The nurses felt it was not good at all to inform the patient. All Gezephi's refusal of the drip and injections were seen as the outcome of the doctors' ideas, which were labelled as being unfair. Nurses felt perhaps a member of the health team, might be told the diagnosis, but even then, not all of them. They felt the patient's personality has to be such that he will accommodate such frustrating news.

##### Researcher:

I was positive to the patient being informed. It forms a good basis on which to assist the patient to co-operate with her course of treatment. One can explain genuinely about the prognosis.

## DISCUSSING DYING WITH THE PATIENT

Doctor:

The doctor informed the patient that her condition was incurable. The patient was happy to have been told. There was a language barrier between the doctor and the patient and this, it is felt, limited further discussion.

Nurses:

The nurses did not discuss dying with the patient. They just said the patient must put everything to God. When asked whether they discussed dying with the patient, they all felt it would destroy her and that it was not cultural to discuss dying with a person who is very ill.

Researcher:

On 1 June the patient called for me to say she was dying. She instructed that I write messages to her children and read them back to her. Besides what has been quoted, she also expressed her wish that she wanted her corpse to be dressed up. She said "I want my Christian friends to see me as they knew me. I don't want to be wrapped with cloths, like a tramp."

On 10 June the patient again said she was dying and called for me. When the attack was over, I asked:-

N: "How did you feel when you said you were dying?"

P" "I was choking and afraid, and just saw everything going blank. I think it is better to die in your sleep than to die awake."

N" "What is it that you are most afraid of?"

P" "It was the choking and not being able to breathe, and dying. I even forgot to pray."

N: "Do you still feel you want to die at home?"

P: "Yes, but I have to be sensible - there is no one to care for me at home. So, I am better off here with doctors, nurses and you, my angel."

On the night of 13 June Gezephi refused the injection and said nurses must leave her alone to die. On the 14th June, I asked her what or how she felt. She said the pain was so severe that she felt she could as well die.

On the 21st June at 09h20 I was phoned by the Sister who said, "Please come, your patient is gasping." I found the Staff Nurse with the patient. She told me that the patient had just been put on oxygen. The patient had not had the sedation since 02h00 as it was out of stock. She told me it had been requisitioned and had come, but the patient was to get sedation only at 14h00. I asked why they were waiting for 14h00. She said, "It is Sister's idea." Sister was called and in this case just asked directly why the patient had not had sedation. It was shocking to hear her say that they give sedations routinely at 14h00.

When the sedation and suctioning had been done, I asked the Staff Nurse:-

N: "How do you feel remaining with a dying patient?"

S/N: "I am afraid, but I just pray."

N: "Why is there nobody remaining with her?"

S/N: "It is difficult, Matron, to see a person die. We suction, give oxygen and go away."

The patient was left with an elderly Nursing Assistant who volunteered to remain with the patient for me, as I had to attend a meeting at 10h00. At 09h55, I dashed to the ward to check on the patient. I found her behind a screen. There was no Nurse with her. Sister was asked why. She said the Nurse had gone for tea from 09h30 to 10h00. The Nursing Assistant just came back. She came and told me that she had failed to find somebody to relieve her. So, she had left for tea at 09.40. There were three sisters, six student nurses, five staff nurses and five nursing assistants. They were all afraid to remain with the patient. So I went to the meeting.

At 13h30 I went back to the ward.

P: "O! My child I am in pain. I am happy to see you. I want to spit!... O! Nothing is coming out." (I held for her the sputum mug. She was dyspnoeic and sounded very chesty. Her forehead was cold and clammy. The pulse was fast and feeble. I re-adjusted her oxygen mask and propped her up, with the help of the same Nursing Assistant. I then relieved her so that she could go to lunch. She had been with the patient since I left at 09h55).

N: "How do you feel now?"

P: "It is the pain! It is the pain! It got me right through the night, there was no injection."

N: "Alright, mama, we will give you the injection again." (She had been given one at 10h00).

P: "I am sure they have been instructed by you. O! Child of God, I appreciate how you care for me. Even when I come before the throne of God, I shall ask Him to send His angels to bless you."

(She coughed. She was assisted and she brought up thick brown, foul smelling mucus. She seemed to have been struggling to bring this up. It gave her some relief).

N: "Thank you, mama, for the blessings. Do you feel you are dying?"

P: Yes, my child, I am going today. I just pray that when the time comes I just "break" and enter the next world without pain. I also wish I do not get any pain during the night. God can take me, I have no objection. Let His will be done!"

N: "Well, mama, if you go, we shall meet in the next world. I shall phone the ward during the night to find out how you are. Keep on praying, and trust that God has said He shall not leave us alone. I am going back on duty, I shall come back."

P: "No! Who is going to remain with me?"

N: "Here is the nurse to remain with you. If you want me, tell her."

P: "I want my eldest daughter."

N: "I shall phone for her. If I do not get her or she cannot come due to transport problems, what should I tell her?"

P: "Tell her to take care of her younger sisters and she must be good to them. O! I do not know what I would do without you. O! Person of God, you have cared for me so well. It has been wonderful, my child. May God bless you. O! My end has come."

The patient lost consciousness while the Nursing Assistant and I held her hands. She remained unconscious until she died at 04h15, on 22 June.

The Family:

The family discussed the family problems with the patient, but not dying. When they were asked why, they said it was not Zulu culture to do that. It would hasten her death in some way.

## FAMILY REACTION TO PATIENT'S DEATH

There was immediate acceptance of death as it had long been expected. The daughter sobbed quietly, but there were no violent outbursts.

## DEATH RITUALS PERFORMED

The patient was buried at Mapumulo during the week, and it was difficult for me to attend the funeral. I met the family at the mortuary. A prayer was said and a hymn sung. The family present were the three daughters and the son-in-law. They said they would not take her spirit as there was no elderly person. That was to be arranged for a later date.

On their return, I asked the Nursing Assitant's mother, who attended, about the rituals that were performed. She told me the goat had been slaughtered. The funeral was conducted in a Christian manner. On return from the graveyard there were two basins at the gate entrance. One had plain water and the other had stomach contents added to the water. The hands were washed by the family and neighbours to remove the death pollution. The family wore a mourning sign.

I asked whether the son was present. She said he came in the evening of the day before the funeral on the 28 June. The daughters regarded this as a way of avoiding responsibility - to come at the last minute when everything had been prepared. The second washing of hands ceremony was to be on 20 August.

On the 19 August the son came to the hospital, accompanied by an old uncle. The uncle was carrying the ziphuf-mucronaea twig for taking the spirit home. So, I accompanied them to the ward. The twig was placed on the floor at the ward entrance. The old man called "Gezephi, come. It is your uncle calling you. Let us go home to Maphumulo." The uncle then kept silent until we reached the car at the hospital gate. He got into the back seat. He spoke to the spirit, informing it they were getting into the car.

I gave the son the mother's messages. He cried and said, "Nurse, I have heard about all your concern and care of my mother. I am so sorry she died. I have to turn over a new leaf, otherwise the curses shall befall me." He was comforted and encouraged to keep up that determination.

Gezephi's son was asked about the rituals that were to be performed for the second washing of hands ceremony. He said they had made Zulu beer and slaughtered a goat. When they reached home, the uncle was to talk in the mother's bedroom so that she can join the ancestors. The following day they were to be joined by the neighbours. In the morning they, as the family, were to wash hands with water to which had been added the stomach contents and the bile. The mourning signs were to be removed and burnt outside the fence. The neighbours were to come at 14h00 and they would pray and then feast on meat and dumplings.

I thanked the son for his initiative to see me and to perform the rituals for the mother. I also asked him to thank and greet the rest of the family. The son also gave me messages of thanks for the doctors, nurses and the researcher, from the family.

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MRS LIZZY X.

Next to Gezephi as on 24 May, there was a 52 year old mother of eleven children - five boys and six girls. She was quite big and weighed 96Kg.

The Night Superintendent, after handing over the night report said:-

N/S: "Mrs Mtalane, there is a young woman in the surgical ward, who was admitted last week. She has been in section three. She went for an operation yesterday. The doctors opened and closed her, as she has inoperable cancer of the pancreas." (She was tearful).

N: "Do you want me to see her, or is it somebody I know who wanted me to visit her?"

N/S: "O, please, can't you take her as your research case?"

N: "I am still handling two cases."

N/S: "O! Please, even if you just visit her casually. You know those doctors are going to tell her about the diagnosis. It would be nice then if you assist her. She has many children. You can arrange for her even about these children. You know she can die happily if she has somebody to talk to, and a person who can assist her."

N: "I shall visit her then."

N/S: "She is in the bed next to your research patient."

I met Lizzy on the 24th May, when I was through with Gezepi. I introduced myself and told her I was to visit her, and that if she has any problem - physically, spiritually or emotionally - she could discuss it with me. I told her I also visit Gezepi.

Her case sheet indicated that she had been admitted on the 16th May. She came in complaining of jaundice and itchy body for three weeks. Her post-operative diagnosis was laparotomy, inoperable cancer of pancreas, cholecystectomy, hepatico-jejuno anastomosis. Her breasts were so big that they overlapped the operation site. I assisted the senior nurse to support the breast and get it off the suture line. As we did that, Gezepi turned and looked with a very jealous eye.

Lizzy was married, had a husband, and 11 children ranging between the ages of 22 years and 5 years. They were Lutherans and lived as a family at Mtunzini. She had had no serious illness before, except dilatation and curretage, and incision and drainage of the breast abscess. Her condition was satisfactory post-operatively. On leaving

I went back to Gezepi and said, "Here is another Christian friend. She is also a Lutheran." I beckoned Lizzy and introduced her to Gezepi. Gezepi relaxed and laughed. So I left them talking to each other.

The next day Lizzy told me that her illness had started in April. She visited four private doctors. She was treated with injections, tablets and mixtures. So, she just decided on her own to come to hospital on 16 May. She had been to X-ray three times, and to ultrasound. Doctor told her she had gallstones and advised her to go for an operation. She said "Nurse, it was the first time since I have been ill that the doctor told me what is wrong. I also liked their approach. They told me when I came that they are going to investigate first. I like this hospital!" She was so happy as she expressed this.

The patient expressed worries about her children and the husband at home. She felt her husband was exhausted because of having to come to see her each day when he came from work, and having to care for the children. She said she had persuaded him to come only on Monday, Wednesday and Saturday. The husband just continued to come even more frequently.

On the 2nd June when Gezepi was critically ill, Lizzy expressed her concern that she was dying next to her. I asked her what she exactly feared. She said it was because she was ill, and worried about the gallstones. She had never heard that a person can have stones inside her and still live. An anatomy book was used to show and explain the biliary system to her. She understood. We screened Gezepi and Lizzy was happy. I asked Lizzy about her thoughts and feelings at such times when she feared for life. Lizzy said she feared the unknown future. She was asked what strengthened her when she felt insecure and she said it was prayer. So we often prayed with Lizzy.

Lizzy had alternate sutures removed on 3 June. She was happy with the nurses and doctors. I met the husband on 3 June and he explained to me that those gallstones seen by the doctor were actually "idliso". He felt people were jealous that they were a happy family. He also felt he had not slaughtered anything for his late parents, and was

sure they had slackened their protection. When Lizzy was discharged, he was going to perform the slaughtering ceremony.

On the 8th June, Lizzy was fit for discharge and to return to the surgical clinic. She has never returned. My notice still hangs in the surgical ward admission room, that I be told when she is admitted.

Whilst Lizzy was in the ward I asked whether they felt happy or not, that she was not told about the cancer of the pancreas. Sister said, it is better if the patient does not know about the cancer. She said the patients die sooner if they know they have cancer. Sister said the worst of it all is that the patient becomes very difficult to nurse, whilst the doctor who told the patient, strolls by on his ward rounds. The Enrolled Nurses said it was very unkind to tell the patient.

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On the 10th June when I went to see Gezepi in the morning at 09h15, I was approached by the Sister. She asked if I could not take another patient for research, who had just come. Sister was asked whether the patient could talk, she said, "I think so."

When I reached the patient's bedside in section two, there was the patient's 22 year old son who was crying. He was accompanied by two women who were their neighbours. They were also sobbing. I reached for the patient who looked semi-conscious, and positioned her head properly. When I turned to Sister who had led me to the bedside, she had vanished. I then realised I had been led to what they considered an unmanageable situation.

I introduced myself to the three - and the son asked me:-

S: "Matron, do you think she is going to make it? (He cried).  
O! No, no, - she will not."

N: (I held his hand and wiped his tears, which he just let run down). "Alright, you have made an assessment of her condition, as you have been with her. Now let us go to the other room so that we can discuss this whilst nurses suction her."

We all moved to an empty side-ward. The son told me the mother had been ill for some time. Since the evening of 9 June she was just dopey, until she called the neighbours in the morning. They phoned for the ambulance. He told me that he and his mother lived alone. He had no father, no sisters and said, "Now my mother, the only hope, is just vanishing!"

N: "Alright, you have a right to feel like that. Mama is very sick. Doctor is going to assess her and tell us how she is. There are difficult times for all of us. If God takes mama, you are big enough to be responsible for your own affairs." (He nodded as well as the two women, whom he called "aunt").

Aunt: "Yes, nurse, there are such difficult times in our lives."

Son: "I have been having this feeling that my mother is ultimately going to die. She has been losing weight, coughing and complaining of headaches all the time. I could see she was getting weaker and weaker. but well, it seems it has come."

N: "If you have been feeling like that, then you should have been planning what you will do."

Son: "Yes, nurse, I did. I have saved money, and I have addresses and telephone numbers of all the other close relatives."

N: "Now we have to wait and see what happens. Mama cannot speak now, so there is nothing to be discussed with her. What strengthens you at such a difficult time?"

They all at the same time said, "Prayer." So, we prayed together. The Sister that had vanished, came in as we prayed. I then took the full name of the son, telephone number at home and at work, and those of the two aunts. They were all grateful. They asked to see her before leaving. We went to the bedside, I let the son hold the mother's hand. He smiled, and said, "My mother can feel it is my hand, look, she is gripping it." We were all happy and they suggested they leave. So I went out of the ward with them.

In the morning, I saw on the night report that she died at 23h00. The Night Superintendent reported that she phoned the aunt at 04h00, as she feared breaking bad news directly to the son.

When they came for the corpse, two days later, they had to collect the patient's kit from the ward. The son asked for me and was escorted to my office. When he came in he said, "Hallo mama, see I am not crying. I am brave and going to bury my mother." He was praised for the courage. He told me he had come to thank me for the support given on that "cloudy" day.

A month later, I asked the Sister who had led me to the dying patient. She was shy, but told me, she just felt I was the right person to talk to the family who were so upset. She said, to see a young man crying was an unfamiliar incident, and she had felt like crying herself. She was just too grateful that I helped them out.

## CASE NO. 10 : MR MAXON X

## INTRODUCTION

Mr Maxon X was a sixty year old bachelor and an eldest son in a family of three. He was from the Kwamthethwa area, in the Empangeni district. He was hospitalised on 28 April, 1988.

## ON ADMISSION

The nurses' interview sheet indicated that he was admitted in a helpless condition. He was very emaciated, dyspnoeic and this was aggravated by a persistent cough. He brought up blood stained sputum. He complained of dysphagia.

The doctor's notes indicated the above stated signs and symptoms and that the lungs were congested. The feet were swollen. The patient was an old pulmonary tuberculosis and had complete neoplastic stenosis of the oesophagus.

He was admitted to the male medical ward for one day and was transferred to the surgical ward on the following day. He was sent to the operating theatre for a bronchoscopy and insertion of the Livingstone tube.

## FAMILY BACKGROUND

The patient was a bachelor and stayed at his home. His parents were deceased. His brother and sister had left home to stay with the other members of the extended family. They quarrelled with Maxon and could not tolerate each other. But since he was very ill the sister had returned home in an attempt to assist him.

The patient's younger brother was married and worked at the Paper Mill at Felixton. His sister was about to get married. He complained that the "lobolo" had not been paid to him. He wondered who had given permission to the grandfather to receive the "lobolo."

The patient made his living out of poultry farming and a banana orchard. He also received a disability grant, as he had been somewhat handicapped in his lower limbs. He used a walking stick, but at times used crutches. He told the researcher he used what suited him, according to where he was going. He said he enjoyed staying alone, as his siblings were full of nonsense.

The patient was educated and spoke English satisfactorily. I asked him what standard he passed at school. He said he passed standard six of the Royal Reader. The whole family were Anglicans.

#### RESEARCHER'S FIRST ENCOUNTER WITH PATIENT

I met the patient in the male surgical ward. It was 08h30 on 2 May 1988. He was sitting on his bed, resting on the backrest. He was wearing his own private pyjamas and a checked gown. He was well groomed and appeared to be a self-respecting person.

I greeted him and after introducing myself, he introduced himself. I said, "There is something I would like to discuss with you about your illness, for research purposes. I would like to sit here next to your bed." He responded in English, "Welcome, take a seat, matron." He questioned me about my parents, and afterwards he told me that he

knew my father from Mtunzini, where he was a court interpreter. He knew my father was deceased and he asked me about my mother.

I realised in this first interview that Maxon was very talkative, and at times, deliberately ignored a question which he did not favour. I was able to get the above family background, on the first encounter. He spoke steadily and with emphasis. He had a mannerism of "you see", "that's it" - even as we spoke in Zulu.

The patient gave verbal consent for being interviewed for research purposes. He read the written consent and said, "You see, I trust you. I even know your parents." When it came to the use of a tape recorder, he said, in English, "You see, I am a very well known person. My voice will be so easy to identify."

#### ILLNESS HISTORY

##### Previous Illness:

He told me he was injured at work in 1963 and that was what caused him some weakness of the lower limbs. He even remembered the name of the surgeon that operated on him. Besides that injury, he had haemorrhoids on and off. Now and again he had been worried by dysuria. He told me the problem of dysuria ended up in 1981 when he went to the chemist and demanded to see the pharmacist. He was given tablets and told to drink a lot of water and that was the end of the dysuria, until 1985.

The patient then looked on either side, as if checking who was listening, and said, "You know, it came up again. I then had to think and "shake my head bones." I thought and concluded that it was a Zulu disease."

N: "What are you saying, now? As you call yourself a "Royal Reader", didn't you learn about germs?"

P: "Yes, I am a "Royal Reader" at work, where I earn a living, but a Zulu at home. I can be bewitched like any uneducated person, and that's it." (We both laughed).

The patient said that he had been using the chemist tablets and some herbal mixtures ever since.

**Present Illness:**

The patient said the disease started from his lower abdomen. It felt like a rod, to start with. After a few months he felt as if this rod was twisting and moving up to the epigastrium. He spoke with signs and invited me to palpate the abdomen with my hand. He showed me where the rod had gone up to the chest. He showed me a swelling on the mid-chest. When I palpated the lump, it was just a soft growth. He then said that lump prevented food going into the stomach. The lump would even cause him to bring up some bubbles, in its struggle to prevent food going down. He had thus lost weight tremendously.

He was asked what he thought caused this illness. He said it was obvious and "needed no interpretation" that it was witchcraft. He said that the urinary problem he had was caused by a bad muthi of an evil person, who sprinkled it on the path and he had walked over it. It then went up to his urinary bladder and caused the urine to boil, thus the burning micturition. The patient expressed his conviction that he had been bewitched by "idliso" at that time.

The patient expressed his amazement that the evil person can bewitch a useless person like himself. He had no property to be envied. He, also, had taken the precautionary measure of licking crocodile fat once a week, to prevent the effects of any "idliso". He said he was going to see how the doctor cured "idliso". When I asked him whether he had confidence in the doctor, he said he did. He said the doctor had told him he was going to examine him in the theatre.

#### PATIENT'S KNOWLEDGE OF DIAGNOSIS

After the bronchoscopy and insertion of the Livingstone tube, the doctor informed the patient that he had carcinoma of the oesophagus. The patient said that it was understandable that the doctor saw "idliso" as cancer, and incurable. He decided though, to wait and see how effective the inserted tube worked.

The patient said it was funny that the doctor said he had cancer when he feels so strong. He told me people suffering from cancer are thin and miserable. He asked for a pass-out the next day. Doctor allowed him to go home and return when he felt ill or uncomfortable. He left the hospital on 6 May and returned on 19 May.

On return he looked very miserable and emaciated. He said it was uncomfortable to swallow with the tube in situ. He wondered about the effect of a foreign body in his oesophagus. He told me that he looked terrible with the loss of weight. It meant his suits were just going to hang, as if on a coat-hanger.

The patient one day told me about his ordeal in the operating theatre. The doctor asked him to swallow the tube. So, it went in, and then he coughed it out and messed up the whole area. He thought he would be scolded, but no nurse or doctor scolded. The doctor then put him to sleep and the tube was then inserted. He then complained of the drip and showed me the swollen arm. He wanted to try swallowing. He claimed the doctor did not come to him during the ward round. The doctor's team system was explained, and he understood.

The next day he told me that the doctor had seen him and discussed his prognosis. He said doctor had asked him to be positive and accept that the tube was going to assist him to have something in his stomach. He told me his own guess was that he only had a few years to live. "O, my child what is there to live for. It is better to have a sudden death." I said, "But also Zulu culture says it is better for a person to be ill, rather than just to die suddenly." He laughed.

In the following weeks the patient told me:-

P: "You know I have been thinking about this illness. I think it is worms, but the special type. When I was on a pass-out, I

tried the worm treatment, and purgatives and herbal mixtures, all in vain. These worms are just here in the stomach.

N: "It is better that you discuss other treatment with the doctor or me, before you strain yourself."

P: "Where was doctor or you, at home? I did this when I was on pass-out."

N: "It is not good to use too much of everything or to mix medical and traditional treatment."

P: (Laughed). "Yes, nurse, but you see I just wanted these worms out. You see they are sucking all my food nutrients and I am getting thinner and thinner -- and you see, doctor says its cancer."

The patient only accepted that it was cancer and that he was dying in mid-July, when he was actually dying. He was then calling cancer as a devil and a monster. He even sorted out his will, and sorted out the "lobolo" dispute.

#### FAMILY REACTION TO KNOWING DIAGNOSIS

The brother and his wife, and his sister were very concerned about the patient. They worried that he had no wife. They were encouraged to see themselves as his support. They accepted this responsibility.

They first felt the brother was rather too fit to be suffering from cancer. As the weeks went by, they saw his condition deteriorating

and they accepted that he was dying. They were afraid to discuss this with him and came to see me. When the patient was critically ill, they assisted him in settling the dispute about the sister's "lobolo" with the grandfather. They performed the slaughtering custom, and the patient received a pass-out from 12h00 to 16h00 to attend. He was taken out and returned in the brother's car.

#### PATIENT'S RELATIONSHIP WITH CAREGIVERS

Doctors:

The patient was positive and at times negative about the doctors. The doctor's team approach confused the patient at times. When he saw a doctor walk past his bed, he got fed up. On the 30th May, when he was refusing to eat and the drip, I came to see him at 13h10.

N: "How are you today?"

P: "I don't know because it is the secret of Sister X, and the Doctor. You know, I asked for a pass-out to collect my pension fund. So, when Doctor and Sister X came to my bed, Sister Z called Sister X. They whispered to each other in section four. (The patient was in section two). Sister X came along to me. They stood at the bottom of the bed and spoke in whispers with the doctor in English, as though I am "no school" (illiterate). Do you know what was the outcome?"

N: "Do tell me."

P: "The doctor said I can go home if I so wish - but sign a refusal

hospital treatment. He said I can come back if I feel like it, and he walked away. So I gave up my request and relaxed."

N: "I can still talk to the doctor."

P: "No, don't worry. I think they told the doctor that I will not return."

N: "Won't you return?"

P: "I will. How can I run away with cancer? You see, Sister Z will see you talking to the doctor and she will tell Sr X and they will ill-treat me. I know the attitude of the nurses, when they have been reported. I made a good study of the nurses when I had met an accident in 1981. I was hospitalised for seven months - so I know what I am saying when I say they will ill-treat me."

N: "Are you sure you do not want to go anymore?"

P: "I am really sincere about that. In fact, it was just a fuss. My brother can collect that money for me."

N: "I think it would be good if you discuss this with the two Sisters and clear up your feelings."

P: "It is alright. I will do that, my child."

N: "I am happy to understand you are determined to be managed by the Doctor."

Nurses:

Besides the above incident the patient was happy about the nurses. I told the nurses that the patient can speak English - so that they could save time on interpreting for the doctor.

Researcher:

The patient regarded me as his daughter and spoke out all his feelings. One day, he even told me of one of the Sisters on the staff who refused to marry him. He was scornful that she refused his marriage proposal and married a man who is a failure in life. He laughed when I said it was not his correct rib and that it seems the Almighty did not take a rib from him to make him a wife, as he was still a bachelor.

When he was disturbed in his mind about his prognosis, he discussed that freely with me. We shared jokes, fears, frustrations and his feelings about the future.

#### CAREGIVERS SUPPORT OF FAMILY

Doctors:

The doctors never met the family. The patient only informed the family of the positive facts about doctors. They in turn praised the care of doctors.

Nurses:

The nurses reassured the family, that they should trust in God.

When asked whether they discussed the patient's condition with the family, they felt anybody could see for themselves that the patient was dying.

Researcher:

The family discussed their feelings and observations of the signs of the impending death with me. We discussed the dispute about the sister's "lobolo" and we assisted the patient to settle this. They were asked what strengthened them at this time. They said it was prayer as a family and in union with their Christian friends. So, we prayed together in the office or at the patient's bedside. We formed a strong link of friendship, trust and confidence.

#### PATIENT'S FAMILY WORRIES

Although the patient claimed not to care about the members of his family who had left him alone at home, he one day said he was feeling lonely, just like he did at home. The worry about the sister having left home and the "lobolo" paid to the grandfather, was obvious.

The patient one day told me that he thought about the time he wasted in Durban. He said he was a "nice-timer" and that was why he never got married. He said even when he reached forty, he remained an arrogant bachelor. He laughed and said, "Look, now I am sick and have no wife to visit me. Oh! But God provided you, my child. You are so concerned and caring."

## FAMILY SUPPORT TO PATIENT

The brother and his wife were very concerned about visiting the patient. The brother's wife brought nice food in very decent utensils. When this was commented on, she said, "My brother-in-law is a very critical person. He is just "high class", and one has to come up to that standard, if you want him to be pleased. A person's likings and dislikes do not change when he is ill.

The extended family came with the Christian friends and prayed with the patient. The patient appreciated this. There was always a decent table doiley on top of his locker. The sister came and reported about his property.

The patient expressed his gratitude that the brother and sister-in-law had assisted him to settle the dispute regarding "lobolo" with the grandfather.

## INFLUENCE OF RELIGION ON PATIENT TOWARDS DEATH

The patient believed that the fate of his life was in the hands of God. He said that prayer strengthened him. He appreciated the visit by the family and the Christian friends, who always prayed before they left.

He stated that it was in the Christian and traditional beliefs that the slaughtering ceremony had to be performed about the "lobolo". The patient was happy and said he felt spiritual relief, and even said that he would die happily.

## CAREGIVERS ATTITUDE IN INFORMING PATIENT ABOUT DIAGNOSIS

Doctors:

The doctors discussed the diagnosis and prognosis with the patient.  
The patient appreciated being told.

Nurses:

The nurses were negative and did not see the point and reason that the patient be told his diagnosis. Each time the patient refused treatment, they blamed the doctors who told the patient he had cancer, particularly when he became difficult and fussy.

Researcher:

I was positive to the patient being told. I further attended to the patient's worries, fears and frustrations. The patient found in me a person to discuss and confide all his anxieties in and any form of problem he had.

## DISCUSSING DYING WITH PATIENT

The patient only accepted that he was dying when he became helpless.  
He said:-

P: "Nurse, my child, I am slowly getting more and more helpless.  
It means I am going to leave this world."

N: "I take it that is what you feel physically." (He nodded).

Emotionally and spiritually, how do you feel?"

P: "I talked to my brother to tell my grandfather that we must settle the dispute. He must continue to arrange for the wedding. He will come back tomorrow. This has been worrying me in my mind and soul."

N: "That is good. Is there anything that you also want to plan for?"

P: "Well, nurse, I had made my will and all is sorted out. In May when I got a pass-out I went to the lawyer to re-frame the will. You see, doctor had told me I have got cancer. I am ready to go now."

N: "What strengthens you at this difficult time?"

P: "I have given up my life to the Lord. I get such joy and happiness when hymns are sung and prayers said. I also pray all by myself."

N: "I am happy to hear that."

The doctors talked to the patient about his incurable condition. The nurses were afraid to discuss dying with the patient and they told the researcher, when asked, that it would hurt the patient's feelings.

The family discussed all their feelings with the researcher. They prayed with the patient each time they came. In their prayer they asked the Lord to relieve him from the suffering and pain.

## FAMILY REACTION TO PATIENT'S DEATH

The family accepted the death of the patient immediately. The brother said they had given up hope as from mid-July, when his condition sharply deteriorated.

## CAREGIVERS REACTION TO PATIENT'S DEATH

The doctors, nurses and the researcher immediately accepted the patient's death. The doctors and the nurses pitied the researcher for the death of her patient.

## DEATH RITUALS PERFORMED

The family was met at the mortuary. We sang a hymn and said a prayer before they left. The grandfather had the ziphuf-mucronaea twig to take the spirit home. He just spoke once, "Maxon, we are now going home by car. Let us go."

The family left and said they were to hold a revival meeting the whole night. They were to bury him on Saturday 23 July at 14h00. They were happy I was going to join them. The brother repeated the directions to their home.

On 23 July, the funeral service was in church and then proceeded to the graveyard. All was done in a pure Christian manner. When we returned home, there were basins at the gate entrances. One with water, and the other with water to which was added the stomach

contents for the first washing of hands ceremony.

The brother was asked about the rituals that had been performed and to be performed. He told me they had slaughtered an ox, because they respect him as the head of their family. The following day, they as males were to get their heads shaved, as well as the children. The children were to wear black neck mourning strings, and the adults mourning signs. These would be removed on 20 August, when they perform the second washing of hands ceremony.

After the washing of hands at the gate entrance, the people were served with rice, vegetables, stew, served on plates. After that cold meat and dumplings were served. Everybody had to sit down on mats in the traditional manner. I asked about the twig. He said the grandfather put it in the kitchen where there was Zulu beer and meat, and where ancestors often visit. The brother was told that they would be joined on 20 August.

On 20 August they had slaughtered a goat. In the early morning the children and adults had removed the mourning signs. They had been burnt by the grandmother in the early morning outside the fence, to prevent recurrence pollution. They had also washed their hands with water to which had been added stomach contents and bile. I was also taken by the old lady to wash my hands, as they felt I was as good as a family member.

At 14h00 a hymn was sung and prayers said. The brother stood up to introduce me and told them I cared for his brother. Everybody said,

"Hallelujah". They expressed their wonder that there are still good nurses. I also thanked the family for their good spirit, and the neighbours for supporting them and the patient.

On departure I thanked the family for all their co-operation in answering my numerous questions. They also thanked me. I asked them what other rituals were to be performed. They said that at the end of the year they would slaughter and perform the "buyisa"/return home ceremony. I informed the brother that I would not be able to come. They were wished all the success. The grandmother kissed me and blessed me on behalf of the family.

#### MR REUBEN X

In the first week of July Maxon showed me a neighbour patient, whom he claimed was lonely and often neglected by nurses. He urged me to talk to him, too. I obliged. The patient was diagnosed as terminal cancer of the stomach. He had secondary cancer, even in his ribs.

I approached the patient with a view to assisting him if he had problems. He told me he hardly had visitors, and that he is not given his sedation regularly, which the doctor promised he would prescribe. His treatment record proved his complaint correct - sedation was irregularly administered.

My observations of the patient was a very dry skin, dry lips and sore mouth, although it looked like it had been cleaned. His suture line was clean and tight with tension sutures. As he showed me where he

had pain on the abdomen for me to palpate (and I did), I saw that his hands were very hard and dry. A student was called to assist me put him comfortable on pillows. His back was rubbed. We then lubricated his lips and hands. He smiled. Maxon commented, "I told you, this is a proper nurse."

The patient was asked about his illness. He told me that he got this disease through "idliso". The doctor was calling it cancer. He said whatever it was, it was slowly destroying him. It had reached incurable levels. He had gone to various witchdoctors, and had been given emetics, which failed to take out the "idliso". He had asked his employer to be released to come to the hospital, but was refused permission until he was very ill.

On the next day we discussed what made him feel that he was dying. He said he just felt as if his body functioning was coming to a standstill. He felt so helpless. I asked him what strengthened him at such a trying time. He said it was his faith in the Lord, that when we die, we shall then meet Him. I asked him whether he would like that we pray together and we did. In his prayer he asked that God releases him from the pain he had suffered. I asked whether he had settled his family matters. He said his only estate would be the pension fund and leave gratuity. He expressed his gratefulness that we had discussed just the things that have been making him worry in his mind.

The patient was visited until his death on 8 August. His family was met at the mortuary. His wife said, "Thank you for what you did for

my husband. He told me that since you started visiting him, he always had his sedation, and he would be free from pain and even pray."

Well, Maxon could no longer comment!

#### MISS ELIZABETH X

The Nursing Assistant who was somewhat related to Gezepi met me in the passage. She looked as if she wanted to say something, so I called her. She told me that there is an old lady, as Gezepi, who had cancer of the oesophagus. She wondered whether I could not take her, so that she can be helped. I asked her what was the most important thing she thought my research helps the patient with. She said, firstly it is that the patient has at least somebody to discuss her illness with, because for sure doctors were going to tell the patients. Secondly, the spiritual support, she felt was very important.

I visited the patient. She was a very talkative, jocular person. She was kneeling on her bed, and talking to another patient. She was visited twice, I managed to get her illness and family histories.

Elizabeth said she was bewitched through "mahewu" (fermented drink made from mealie-meal porridge) at a party. She remembered how she felt a grip on her oesophagus as she swallowed. She had to run out to vomit and she brought up a roundish sputum. She had gone back to the house to call a relative, and when they returned the sputum had disappeared. She said the suspected witch must have seen her go back

to the house, and then disposed of the sputum. The bewitched "mahewu" was referred to as "idliso". This "idliso" left a lot of poison inside her oesophagus, and this is what doctor was referring to as cancer. This "idliso" was blocking her oesophagus. She had often felt something was coming out, but it never came up because the "idliso" was stuck up on the lining of the oesophagus. She ultimately could not swallow food, except fluids. This had left her thin as a rake. She stretched out her arms to show me how thin they were.

The patient told me that she had a Celestine tube inserted on 8 June. She said the tube was uncomfortable and she felt comfortable in a kneeling position.

On the second interview, she told me that she was single, but had had a child who died twenty-five years ago. She said that her fiance left her when she was pregnant. She was so disappointed that she never trusted a man again. She was orphaned in her early adulthood and stayed with her uncle's (younger father) family. They cared very little about her. So, she only expected friends to visit. She felt the doctors and nurses were good to her, and I was an additional caring person. She was happy when I sat down to talk to her.

She felt I was a real visitor, especially meant for her. She was feeling lonely being away from home and her friends.

Elizabeth was discharged on 9 June. She was to return when she felt ill.

## CHAPTER 7

## ANALYSIS OF CASE STUDIES

## 7.1 SAMPLE DESCRIPTION

The patients studied were five males and five females. Of the five females, three were married, but all had dependent children. One male was a bachelor, two were married and four of them had dependent children. The bachelor had a married brother who was younger than him and one sister who was about to get married. He was the head of the "umndeni".

The majority of patients studied were dying from different types of cancer, although one had intestinal perforations and a volvulus, and the other one from liver cirrhosis. The former had been told he had cancer until the second biopsy results were negative in the last month of his life. The average age of the patients studied was 47 years, the oldest was 60 years and the youngest 30 years.

## 7.2 ANALYSIS

Content analysis was done on each case and the classification of areas and specifics as in Addendum "A", was developed. After each case had been analysed in this way, a cross-case analysis was done. The fifteen (15) areas will be discussed.

## 7.2.1 Tape Recording of Interviews:

All the patients studied were negative to the tape recording of the interviews for one or more of the following reasons:-

- (i) Fear of being identified (4 patients).

- (ii) Tape recording not acceptable in Zulu culture in that one's voice speaks after one's death (3 patients).
- (iii) One patient connected a tape recording with the police.
- (iv) Two patients just refused the tape recording giving no reasons.

#### DISCUSSION

The unacceptability of the speaking voice after death could be connected to the Zulu conception of viewing people as a single being composed of the physical body and soul. It is in the same sense that Zulu speaking patients refuse operations that involve amputation or excision of certain parts of their bodies, which they say get buried whilst one is alive. Often when incineration procedure with respect to these body parts is explained, the patient is agreeable to the operation being performed. I have experienced this attitude of patients since 1958.

#### 7.2.2 Illness History:

- (i) The illness history given to me by all the patients studied, differed greatly from that given to the nurses and doctors, which was recorded in the patients' files.
- (ii) Initially eight (8) patients studied believed the cause of their illness was "ukuthakathwa" (bewitchment).
- (iii) Two patients said their conditions were of "amagciwane"/pathological origin, but when they were told they had cancer and that death was inevitable, they changed their minds and said they had been bewitched.

- (iv) The site of their disease was related to the alleged mode or method of their bewitchment. For instance, those who had cancer of the oesophagus and the intestinal perforation said the cause was "idliso", and those who had ascites, oedema of lower extremities, cancer of uterus and bladder - believed they had walked over the bewitchment "muthi" (see Addendum "B").
- (v) One patient averred immediately she had been bewitched when she took certain food while the others could not identify the time.
- (vi) One patient had taken precautionary measures against "idliso" by often licking crocodile fat. No one else mentioned prevention.
- (vii) One family believed the cancer was recurrence pollution because the patient's grandmother and mother had died from lower abdominal pains and had a similar offensive smell.
- (viii) None of the patients mentioned angry ancestors as the cause of their illness. All suspected living people and most had a clear idea of who was responsible.

#### DISCUSSION

- (i) None of the patients studied received early western medical treatment because they had been treated by the "inyanga", "isangoma" or faith healer first who is believed to be the only one capable of treating Zulu diseases.
- (ii) The researcher is of the opinion that the idea of bewitchment left the patients with a feeling of being able to find somebody to blame for their incurable cancer. However, it creates negative interpersonal climate and a way of life where there is always suspicion of others.

### 7.2.3 Influence Making Health Decision : Admission To Hospital:

- (i) The first treatment is by the traditional healer or faith healer, or both.
- (ii) The second point of treatment is the private western doctor (Black or White), whose treatment is taken concurrently with that of the traditional healer. In this study the private doctors treated the patients for an average period of three months before referring them to the hospital.
- (iii) The family and the private doctors played a major role in influencing the patients to come to hospital for admission.
- (iv) The patients studied said that they had decided to come to hospital to try the medical treatment and when the doctors said their disease was incurable, they accepted it, as it is understood that the medical doctor cannot treat disease caused by bewitchment.
- (v) Patients studied commented that they had paid a lot of money to the traditional and faith healers and been impoverished.

### 7.2.4 Patients' Reactions To Knowledge Of Terminal Diagnosis:

All the patients studied except one first learned of their diagnosis and prognosis from the western/hospital doctors. One overheard nurses discussing their cancer patients in a Durban hospital. She was, however, also informed by the doctor on her next hospital admission. Their reactions were varied:-

- (i) Shock:

On hearing the cancer diagnosis and inevitable death. At this stage

they knew with their heads that they were dying, and there was anger alternating with depression (10 patients).

(ii) Denial:

Of finality of the prognosis in that the five patients verbalised getting alternative help/treatment from the traditional or faith healers or offered alternative explanation about their diagnosis.

(iii) Acceptance of Reality:

As their physical conditions deteriorated the obvious signs of death in their bodies changed "head knowledge" to "heart knowledge" of their prognosis. They became depressed and withdrawn, what Hinton (1963) referred as a type of "apathetic giving up". The Zulu in their acceptance of death say "ayisekho into eyimi sekusalele ilanga" (there is nothing left of me, it is just waiting for the day - of death) (10 patients).

(iv) Disease Personification:

This occurred especially later in the course of illness, when the cancer was referred to as a killer "crawling" to destroy or as "eating up one" (10 patients).

(v) Two patients wanted to go home to perform the slaughtering custom to contact the ancestors or make peace with living relatives.

#### DISCUSSION

(i) Bargaining as described by Western authors such as Kubler-Ross, when the patient set a deadline for himself to be able to fulfil a particular event, was not seen in this study.

- (ii) There were no clear or specific sequence/stages of the dying in the patients studied. Patients moved from one feeling state to another, and often back again. They, however, all started off with shock on hearing of their diagnosis and prognosis.

#### 7.2.5 Family Reaction To Knowing Patient's Terminal Diagnosis:

All the patients studied informed their families of their terminal state and the families accepted the reality of cancer being incurable and the inevitability of death. Their reactions were:-

- (i) Shock, grieving, suggesting alternative treatment, or performance of the slaughtering customs to contact the ancestors, and/or to augment medical treatment (10 families).
- (ii) There were specific signs that they associated with impending death in the patient:-
- (a) Helplessness
  - (b) Gross emaciation
  - (c) Avoidance eye contact (10 families)
- (iii) Although the patients studied informed their families of their diagnosis and prognosis, there was no further discussion of the issue between patient and family. They gave the dying patients false reassurance, and see any open discussion as hastening death.

#### 7.2.6 Patients' Relationships With Caregivers:

- (i) The ten patients studied felt positive towards the doctors. There was no resentment about being told of the diagnosis and inevitable death.

- (ii) The doctors gave no further support to patients, even when they became angry and anxious or depressed.
- (iii) The patients had mixed feelings about nurses. Six patients were positive to all nurses on day and night duty. Four patients were negative to night nurses who sat far from them in the duty room, and relief nurses whom they did not know. Discontent was often related to specific incidents.
- (iv) Patients studied resented the formal report taking and giving being done in English, which they did not know or understand, and speaking to the doctor about them in English. They also resented being asked about their condition and the nurse writing what they had said without their further involvement (6 patients).
- (v) The ten patients studied were very positive to me for the help given them. In analysing the data, the help I gave them can be classified as follows:-
- (a) **Spiritual Help:**  
I prayed with them when they verbalised a need, encouraged their faith and arranged for visits from the clergy.
- (b) **Social Help:**  
I visited them, brought food, arranged for others to sit with them, arranged for children and family to visit them, and for them being able to perform their rituals.
- (c) **Emotional Help:**  
I encouraged the ventilation of feelings, ensured better care, acted as their advocate, and gave them explanations about their treatment or

medical/nursing procedures.

(d) Physical Help:

I ensured their better care by giving instructions to nurses by virtue of being a matron/supervisor. I sometimes fed them and they tried their best to take as much as they could even when the ward nurses had failed to persuade them to eat.

(e) Financial Help:

Their children were assisted with busfare to be able to visit them in hospital.

DISCUSSION

- (i) I became very involved in giving spiritual, social, emotional, physical and financial help to the patients studied. Indeed the doctors and the nurses asked me to be involved with the other dying patients. This indicated the realisation of the need to give this special care to the dying.
- (ii) I tried in vain to involve the doctors and the nurses in the type of care and support I gave to the patients studied.
- (iii) Because of my involvement in the care and support of the patients studied, I got adopted as a family member, when they verbalised I was part of their family, and they expressed their reliance on me for my continued presence at the hospital.

7.2.7 Family Support To Patient:

- (i) The patients studied were positive about visits by their partners, parents, older children, neighbours, siblings and friends (10 patients).

- (ii) Four patients were hardly visited because of the distance and travelling expenses.
- (iii) The patients studied and their families were negative to being transferred to King Edward VIII Hospital for radium therapy, as they felt very lonely and it was expensive for family to travel (10 patients).
- (iv) The family assisted the patients who wanted to perform rituals of either contacting the ancestors for making doctor's treatment successful or to ease their death.

#### 7.2.8 Caregivers Support To Family:

- (i) The researcher gave support to all members of the families of the patients studied, by:-
  - (a) Being available to them.
  - (b) Openness in discussing their feelings and fears about the dying patients.
  - (c) Visiting the patients on their absence.
  - (d) Taking part in the care of the patients.
- (ii) The ten families studied adopted the researcher as a family member and even involved her in their death rituals.
- (iii) The nurses avoided discussing the patients' conditions with the families.

The nurses, in that avoidance, only greeted the families and created in them false hopes of patients' recovery. They said things like "trust in God", "the patient would be better", or "it is only God who

knows the hour of death".

- (iv) The doctors never met the families of their patients but the families held a positive attitude towards them for their honesty of telling the patients about their terminal diagnosis.

#### DISCUSSION

There was a mutual avoidance of discussing the death topic by both the doctors and nurses.

#### \*7.2.9 Patients' Family Worries:

- (i) Nine of the patients studied worried about their dependent children. The researcher assisted by contacting them and arranging for them to visit the patients to the extent of providing the busfare. For one of these nine, the community psychiatry nurses went via her home on their home visits.
- (ii) Four of the patients studied worried about their partners, parents and married and/or working children.
- (iii) One patient held a grudge against a friend and it was arranged that the pastor saw her in this regard.

#### DISCUSSION

Because the doctors, nurses and the family did not discuss dying with the patients, the patients had only the researcher with whom to discuss all their worries.

7.2.10/11 Discussing Dying With Patients And The Attitude Of  
Caregivers To Patients Being Informed Of A Terminal  
Diagnosis:

- (i) The doctors merely informed the patients about their terminal state through Sisters/nurses as interpreter.
- (ii) The researcher fully discussed dying with the patients. When the patients said they felt they were dying, they described the following feelings:-
  - (a) It is depressing, frustrating, feel helpless, anxious, and the body feels like it is stopping to function.
  - (b) Had a choking feeling and was afraid and everything went blank.
  - (c) Feeling of physical helplessness and feel ready to go/die.
  - (d) When left alone, feels lonely, and it is a painful loneliness.
- (iii) The nurses and family members did not discuss dying with the patients. The reasons given were:-
  - (a) It is not culturally acceptable to discuss dying with the patients/persons in terminal state in Zulu culture. It is believed it hastens the dying process.
  - (b) Fear of how they could initiate such a discussion, and whether they could handle the details of such a discussion.
  - (c) From (b) they feel it needed a special person with a special gift of speaking in a special way.
- (iv) The nurses themselves were not in favour of the doctors informing the patients about their diagnosis and prognosis as they felt it hastens

the death of a patient and it is not an acceptable practice in Zulu culture.

- (v) There was conflict between the nurses and the doctors in this area. Nurses were opposed to doctors who told the patient of his impending death and then became non-committal when the patients showed negative reactions. They verbalised that the doctor "strolls past the patient" whom he had caused a lot of frustration, whilst they (nurses) struggle with the patients' rejection care.

#### DISCUSSION

- (i) It can be viewed as an irresponsible medical policy that the doctors made a unilateral decision to inform the patients about their terminal state, without discussing it with the nurses and ensuring that the nurses are prepared in skills and attitudes, to support the informed patient.
- (ii) The doctors are not aware of the frustrations they had caused the nurses, as the nurses do not communicate this to the doctors.

#### 7.2.12 Influence Of Religion On Patient Towards Pending Death (And Type Of Religion):

- (i) Eight of the patients studied were christians and two were traditional believers.
- (ii) One patient was angry with God in that he had all along prayed that he should not die from cancer.
- (iii) The eight Christians verbalised being strengthened by their faith in God, and prayed that God relieves them from their pain and suffering.

- (iv) The eight Christians verbalised that they shall be with God after death in the next world.
- (v) The two traditional believers were positive to death in that they believed they would join their ancestors in the world of "abaphansi"/underground. They also verbalised that they were strengthened by their faith.

#### DISCUSSION

- (i) The dying patients studied showed no fear of death. They said prayers and their faith in God and their ancestors strengthened them - Christians and non-Christians respectively.
- (ii) Three patients had guilty feelings about their disputes within their families.

#### 7.2.13 Family's Reaction To Patient's Death:

The families studied quietly accepted the patients' deaths when it occurred. They had commenced grieving before the patients' deaths.

#### DISCUSSION

- (i) There was no wailing as deaths had been expected and families' support had already been initiated. Wailing often occurs among Zulus when news of death is received. The absence of wailing in all these cases may be the result of the open discussion and support, which promoted positive grieving.

#### 7.2.14 Caregivers Reaction To Patients' Death:

- (i) The doctors and the researcher accepted the patients' impending deaths as a reality. The nurses started grieving before the patients' deaths.
- (ii) The nurses in their grief gave me the same support as the families. This suggests that the nurses did not see the care I gave these patients as part of their expected care of dying patients.
- (iii) All the doctors expressed sympathy to the researcher for the deaths of "her" patients.
- (iv) Nurses partly accepted the deaths of patients because they felt that telling the patients about their diagnosis and prognosis hastened their deaths. The nurses, however, felt they had given the patients the best possible care, as they all reacted negatively to knowledge of their inevitable deaths.

#### 7.2.15 Death Rituals Performed By The Family:

- (i) The families studied performed both christian and traditional rituals. These were:-
  - (a) The taking of the spirit of the deceased person home by an elderly family member by means of a ziphuf-mucronaea twig.
  - (b) A slaughtering of a goat for enabling the spirit to join the ancestors, and
  - (c) Its stomach contents were added to the water for the first washing of hands ceremony.

- (ii) Three families performed the shaving of heads ritual.
- (iii) Two Christian families wore the black mourning sign/cloth.
- (iv) All the families studied after an average period of two months, performed the slaughtering custom for the second washing of hands ceremony.
- (v) The first and second washing of hands ceremonies were meant to strengthen the families and the neighbours against pollution caused by death.
- (vi) Two patients were buried at the cemetery next to the hospital due to the families' fear of recurrence pollution.

#### DISCUSSION

- (i) All the families seemed to have developed a practice of providing plain water as well, for the washing of hands ceremonies. Plain water was for those who claimed not to be involved in traditional rituals anymore.
- (ii) Those who washed their hands with plain water, however, ate the goat meat that was for enabling the spirit of the deceased to join the ancestors, and these included the clergy.

#### 7.2.16 Dreams:

Dreams are a reality in Zulu culture, as already explained. The two patients told me of their dreams that predicted their death - the one who saw a host of people in white robes; and the other who repeatedly dreamt of his dead friend which linked him to the dead. These dreams intensified the anxiety state.

### 7.3 OTHER VARIABLES AND OBSERVATIONS

- 7.3.1 The attitude of nurses towards the patients studied changed during the study - they tried to meet all their verbalised needs, their treatment recordings were up-to-date and their beds and lockers were kept neat and tidy. In other words, there was improved patient care.
- 7.3.2 My regular visits, bringing food and other forms of support, made the nurses suspect that I was a blood relative of the patients studied, and not just a researcher as what I did has only been seen done by relatives of patients.
- 7.3.3 Patients' dreams and fears were neither recorded or reported to the doctor for appropriate treatment.
- 7.3.4 Some of the patients studied involved their neighbour patients in the discussion of their illness histories so that it became a group discussion. In normal nursing practice we keep things confidential, but these patients showed sharing of their personal matters.
- 7.3.5 On the initial interview (admission) the patient informs the nurse the name he/she prefers to be addressed by and it is recorded. None of the patients studied was accordingly addressed.
- 7.3.6 Patients studied and their families became very dependent on the researcher and withheld their complaints, feelings and requests from the nurses.

This dependence went to an extent that they became concerned about my health (in case it prevented me visiting them) and even how my husband cared for me. Some pitied me for attending too many meetings even on Sundays as they felt it strained me. I always informed them where I could be found in case they needed me.

#### 7.4 SUMMARY

This cross-analysis shows the multiplicity of the human experiences and reactions to impending death by the dying patients, their families and the caregivers. It shows that as Tonybee (1968) suggested, positive intervention in the dying process makes it easier. This study has shown hope for the understanding of the human strengths and weaknesses experienced by the patients, families and caregivers and for which the next chapter gives conclusions and recommendations. Implicit in my findings are ways in which the care given to dying patients should be improved.

## CHAPTER 8

## CONCLUSIONS ON STUDY AND RECOMMENDATIONS

## 8.1 INTRODUCTION

The conclusions and recommendations on this study are based on the intensive interviews the researcher held with ten dying patients who knew about their inevitable deaths. These patients were interviewed and supported continuously throughout their dying process whilst communication was maintained with and observations made of the doctors, nurses and their families.

This study has not and was not meant to give a complete spectrum of the experiences of all the Zulu speaking people, but it has illustrated the anxieties, fears and hopes of the dying patients and their families and the short-comings of the care. For the researcher it was a new experience and a challenging opportunity to refocus on the patient as a human being, to include him/her in dialogues, to learn from him/her the strengths and weaknesses of our medical and nursing management of the dying patients.

## 8.2 CONCLUSIONS

## 8.2.1 The Need To Discuss Dying With Patients:

From the foregoing it is evident that the terminally ill have special needs which can be fulfilled if we take time to sit and listen and find out what they are. The most important communication, is the fact that we let the patient know we are ready and willing to share concern, and give him/her the support on a continuous basis until death. The family have similar needs and should be included in the spectrum of care.

### 8.2.2 The Lack Of Skills And Knowledge On The Part Of Caregivers:

The caregivers (doctors and nurses) lack the skills and knowledge of handling or discussing dying with the patients which would enable them to give the necessary multi-disciplinary support - social, spiritual, physical, emotional and financial - to the dying patients and their families.

### 8.2.3 Lack Of Recognition Of Patients' Cultural Beliefs:

There is lack of recognition of the patients' cultural belief system which contribute so much to the awareness of the uniqueness of each dying patient, his/her perception of diagnosis and prognosis, his/her health behaviour patterns, and his/her acceptance of the medical and nursing care plans.

## 8.3 RECOMMENDATIONS

### 8.3.1 Clinical Nurse Specialist:

It should be understood that a newly qualified nurse and at times an experienced nurse often lacks the ability to communicate with the dying patients and their families.

Dealing with the dying patients requires a certain level of maturity which comes from acquiring skills, knowledge and experience in this role. She will attempt to let the patient know in her words or actions that she/he is not going to abandon them during the dying process. The dying patient picks up these cues and opens up and shares his/her concerns with this nurse.

One solution to this problem can be to create a position for a clinical nurse specialist with responsibility to all dying patients. The clinical nurse specialist will be the patients' therapist and trainer of both students and trained caregivers. The clinical nurse specialist will require financial recognition for her specialised training, and be granted permission, the latitude, the responsibility, and the time to exercise independent decision making and action through approved medical and nursing guidelines.

This may be an expensive option, but the need for clinical nurse specialists is currently widely recognised and actively supported by the profession. It seems to be the only realistic option if the patient has been hospitalised.

### 8.3.2 Hospice Programmes:

Hospice programmes have been initiated in the Natal province since the early 1980's, in the Durban white area, Port Shepstone Black rural area, and Edendale Black area to varying degrees. These programmes are initiated from health centres and directed to the community. The nurses train the families of the terminally ill patients and hospice volunteers in home care. They then make regular checks and can be called if a need arises. The terminally ill person returns to hospital if there are complications or when the family cannot cope with managing the patient at home.

The hospice programme of care is recommended in all KwaZulu areas. The staff nurses who are Community-health-facilitators could train the families in the area she serves, as she is suitably placed there in the community. The Mobile Clinic vans, whose team consists of a professional nurse (Sister) could make the regular check-up visits, and return with patients that require institutional care. The medical social workers, the physiotherapists, occupational therapist in the KwaZulu Regional Hospitals, together with doctors and nurses and community organisations should come together to formulate a teaching programme for the staff nurses. This programme should cover areas of dying, patients' physical, emotional, social and spiritual needs, providing family support, and maintaining interdisciplinary team collaboration involving volunteers in a community-directed, community-centred, and family-based patient care.

This may be a more cost-effective option to address the problem of care of the dying, especially with a view to the threat of AIDS. In the next decade and up to year 2000, the Republic of South Africa will be faced with a lot of young people dying from AIDS, and it is a professional obligation to meet their needs through home nursing and Hospice care programmes.

### 8.3.3 Improvement Formal Medical and Nursing Training on Death and Dying:

The curriculum for the training of doctors and nurses already includes psychology and sociology, which gives them enough theoretical knowledge. It is essential that the lecturer/tutor assists the student in the clinical practice to acquire the skills of listening, tolerance and patience to talk to the patient long enough to establish all the necessary information about illness and feelings of the patient. This will, in turn, maintain the confidence patients have in the nurses and doctors.

The researcher is not recommending more training/teaching, but a careful examination of the adequacy of content and practical application.

### 8.3.4 In-Service Education of Caregivers:

The basic training of the majority of already trained nurses and doctors did not provide them with enough knowledge and skills to give meaningful support to the dying patients. It therefore requires that the hospital sets out its philosophy with regards to care of the dying patients and then supports the philosophy with carefully planned in-service education programmes and staff evaluation.

### 8.3.5 Health Education for School Children on the Causation of Disease:

There is a definite need to add to the Zulu speaking people's perception of the causation of disease, the facts of Western science, so that they will seek medical assistance earlier in the course of their illness. The important target group is primary school children so that they will grow up with a changed attitude to the treatment of disease.

All biological and physical sciences should be taught with appropriate visual aids such as experiments, and any relevant apparatus, so that the children can see for themselves that scientific facts are not a story or a myth, but a reality. For instance, germs should be seen under a microscope to illustrate that they are living organisms.

Health education must not dispute Zulu speaking people's explanations about disease causation, but teach that when there is illness, Western medicine can treat it with favourable outcomes if medical assistance has been sought early, even if it was caused by muthi or idliso.

#### 8.4 CONCLUSION

The complexity and uniqueness of the human experience has been illustrated by this study of dying people and their families and caretakers. We are far from an ideal world in which this lonely experience is perfectly handled. But I hope that this study will make some contribution to a truly humane dying process for many future Zulu patients.

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9. Patient's Family Worries	<ol style="list-style-type: none"> <li>1. Dependent children</li> <li>2. Partner</li> <li>3. Parents</li> <li>4. Working and married children</li> </ol>	
10. Discussions Dying with Patient	<ol style="list-style-type: none"> <li>1. Yes</li> <li>2. No</li> </ol>	<u>Whom</u> <ol style="list-style-type: none"> <li>1. Doctors</li> <li>2. Nurses</li> <li>3. Researcher</li> <li>4. Family</li> </ol>
11. Attitude Caregivers Informing Patient Diagnosis	<ol style="list-style-type: none"> <li>1. Positive</li> <li>2. Negative</li> <li>3. Neutral</li> <li>4. Ambiguous</li> </ol>	<u>Whom</u> <ol style="list-style-type: none"> <li>1. Doctors</li> <li>2. Nurses</li> <li>3. Researcher</li> </ol>
12. Influence of Religion on Patient towards Death	<ol style="list-style-type: none"> <li>1. Positive</li> <li>2. Negative</li> <li>3. Neutral</li> <li>4. Ambiguous</li> </ol>	<u>Type Religion</u> <ol style="list-style-type: none"> <li>1. Christian</li> <li>2. Traditional</li> <li>3. Both Christian and Traditional</li> </ol>
13. Family Reaction to Death	<ol style="list-style-type: none"> <li>1. Shock</li> <li>2. Acceptance reality</li> <li>3. Denial</li> <li>4. Inclusion researcher as family member</li> </ol>	<u>When</u> <ol style="list-style-type: none"> <li>1. Immediately</li> <li>2. After few months</li> </ol>
14. Caregivers Reaction to Patient's Death	<ol style="list-style-type: none"> <li>1. Shock</li> <li>2. Acceptance reality</li> <li>3. Denial</li> </ol>	Immediately
15. Death Rituals Performance	<u>Type</u> <ol style="list-style-type: none"> <li>1. Christian</li> <li>2. Traditional</li> <li>3. Both - Christian - Traditional</li> </ol>	<u>Why</u> <ol style="list-style-type: none"> <li>1. Cleansing Pollution</li> <li>2. Joining ancestors</li> </ol> <u>Traditional Rituals</u> <ol style="list-style-type: none"> <li>1. Taking spirit home with twig</li> <li>2. First washing of hands</li> <li>3. Second washing of hands</li> <li>4. Mourning sign</li> <li>5. Shaving head</li> </ol>
16. Dreams	<ol style="list-style-type: none"> <li>1. Predicting death</li> <li>2. Giving instructions</li> </ol>	

I  
ADDENDUM "B"

G L O S S A R Y

abathakathi	-	sorcerers
abaphansi	-	those underground/ancestors
amabhinca	-	non-believers in Christ
amakholwa	-	believers in Christ
amadlozi	-	ancestors
amashwa	-	misfortune
amathongo	-	ancestors (derived from the noun ubuthongo/sleep)
anorexia	-	loss of appetite
bakkie	-	a vehicle which is a van
cachexia	-	a condition of extreme debility
chief professional nurse	-	senior matron
dysphagia	-	difficulty in swallowing
dysuria	-	difficult or painful micturition
dyspnoea	-	difficult or laboured breathing
knob-kerrie	-	(knopkierie) short stick with rounded head
goduka	-	to go home/to go to join ancestors
godusa	-	to send the aged further (to join ancestors)
makoti	-	bride to a family and to the locality
muthi	-	medicine made up of herbs or animal
Mvelinqangi	-	Creator, Lord of Skies
night superintendent	-	a matron in charge of the whole hospital on night duty
N/A	-	nursing assistant
idliso	-	bad muthi intended to harm or kill secretly added in food, beer, sprinkled on ground by the evil person
induna	-	supervisor in work situation
inzilo	-	mourning sign (often a black cloth)
isangoma	-	diviner
isidina	-	repulsiveness
isibindi	-	liver
isiko	-	custom
isiphandla	-	bracelet made of skin of beast or goat worn around the wrist
iphupho	-	a dream
izithunzi	-	shades/ancestors
izithutha	-	fools/ancestors
izintwala zendoda	-	a man's guarded secrets

paranoid	-	delusions of persecution
SANC	-	South African Nursing Council
sick parade	-	clinic in hospital for sick employees
Sister	-	a registered nurse
sister	-	sibling to the patient
somatization	-	a disorder characterised by recurrent and multiple complaints
S/N	-	staff nurse/auxilliary nurse
S/P/N	-	senior professional nurse/senior sister
ubaba	-	father
ubaba omdala	-	older father
ubaba omncane	-	younger father
udlulile	-	passed on/died
udokotela	-	medical doctor
uhambile	-	gone/died
ukufa/ukubhubha/ukugqibuka	-	sudden extinction/death
ukucela izinhlanhla	-	to appease ancestors
ukugeza/ukuhlamba izandla	-	washing of hands ceremony
ukuthelelana amanzi	-	to make peace
ukuzwa	-	to hear from diviner e.g. what caused the illness
ukwemula	-	a slaughtering ceremony by which a girl is initiated to puberty or marriageable state
umalume	-	mother's brother/uncle
umkhokha	-	recurrence pollution
umlahlankosi/umphafa	-	ziphuf - mucronaea tree
umndeni	-	household; an extended family of two, three or more generations
umnumzane	-	male senior head of umndeni
umnyama	-	darkness/pollution
umsamo	-	far end of hut/house
umswani	-	stomach content used in washing of hands ceremony
umthandazeli	-	prayer man/woman
ukuphekezela	-	to accompany
ukuqinisa umuzi	-	to strengthen by muthi one's household against bewitchment
volvulus	-	twisting of a part of the intestine, causing obstruction