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LIVING WITH CANCER

AN ETHNOGRAPHIC STUDY OF THAI CANCER PATIENTS

Yuwadee Kestsumpun. R.N., M.Sc. (nursing)

A Thesis Submitted in Total Fulfilment of the Requirements for the Degree of Doctor of Philosophy

School of Nursing
Deakin University

February, 1993
In Memory of Bunyong Kestumpun, My Father

A Soldier, An Inspiration, A Guiding Light
I certify that this thesis entitled 'Living with Cancer: An Ethnographic Study of Thai Cancer Patients' and submitted for the degree of Doctor of Philosophy, is the result of my own research, except where otherwise acknowledged, and that this thesis (or part of the same) has not been submitted for a higher degree to any other university or institution.

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SUMMARY

This thesis is an ethnographic investigation aimed at describing the lived experiences of Thai cancer patients residing in Cancer Hostel, a shelter provided for the needy whilst undergoing radiation treatment at Siam Hospital. All names, including the hospital, the shelter, and all respondents have been altered to preserve anonymity.

The practice of withholding the true diagnosis from Thai patients meant that very little was known about their own feelings on cancer and its treatment. That, coupled with entrenched medical practice beliefs, presented an unusual challenge, for which an ethnographic research method was advocated as being most appropriate in helping toward a better understanding of the problem and resolving the existing dilemma.

To understand the real experiences of Thai cancer patients, it was extremely important that the researcher get as near as possible to becoming one of them. Therefore, by physically 'being with', establishing rapport, and gaining patients trust, the researcher was assured of acceptance as an insider, and was thus allowed to share the experiences of their life encounters.

Research findings graphically illustrated the flaws in the practice of protecting patients from their diagnosis, who almost universally, wanted to know more about their diagnosis in order to seek help from the medical care system. Towards this, patients created meaning by linking folk beliefs, culturally inherited knowledge and a common sense, albeit naive approach in trying to make sense of their illness and treatment.

Although patients saw cancer illness and its treatment, especially radiotherapy, as life threatening, it was the fear of radiation treatment, not cancer illness which turned patients away from medical treatment. As well, uncertainty, fear and frustration through the lack of information and involvement in their treatment saw patients employ strategies of both reciprocal and fatalistic acceptance; stoic resistance; and thinking positively in their efforts at coping with those life threatening situations.
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Figure 1. "in hostel", illustrating modal sub trees
CHAPTER 1

INTRODUCTION TO THE STUDY

Introduction

In most cultures, cancer is a word which has the power to create terror in the human heart (Shields, 1984). The word elicits an immediate emotional response (Smith, 1988), a response that seems to have no relationship to either rational thinking (Brauer, 1970), the depth of knowledge of the individual, or the individual's role in society (Woods, Lewis and Ellison, 1989). These same responses seem to occur in all walks of life. The feelings and mental images stirred up by that single word, cancer, make up a complexity of ideas that when tied together, form our concept of what cancer means. Moreover, the view that cancer equals death has become rooted in the psyche of all people regardless of nationality, race or religion. People turn pale at the mere mention of the disease.

For the patient, the diagnosis of having cancer represents a severely stressful life event (Glaser and Strauss, 1965; Kubler-Ross, 1969; Sontag, 1977; Weigold and McMahon, 1985; and Burgess, 1987) and brings about an immediate change in lifestyle as well as presenting a number of problems with which they must learn to cope. These problems, as mentioned by several writers (Burns, 1982; Bond, 1983; Donovan and Girton, 1984) include: (1) The management of knowledge and the control of fear of having a potentially fatal illness which brings many distressing symptoms such as those of disfigurement, wasting and almost certain pain coupled with the disruption to planned life-goals; (2) Along with changed life-goals comes the realisation of coping with an illness that will lead to hospitalisation as well as the onset and progression of a physical and psychological state that usually ends in death; (3) The sufferer must learn to deal with the consequences of their treatment, whether it is surgically created changes in their bodily functions and physical appearance or the chemically induced symptoms of nausea, anorexia and hair loss, as well, there are the immediate and long-term physical problems for those who undergo radiotherapy; and (4) Problems of relationships with others become manifest when the nature of the illness becomes known, in that they may hold different conceptions on how that illness and its consequences came about as well as the different understandings of patients' needs.
In these writings, as well as the many recent studies directed toward cancer patients, it can be seen that the emotional responses of an individual to cancer are far from predictable and depend on many intrapersonal, interpersonal, and environmental factors.

Over the last decade, researchers have recognized the importance of the effect of cancer on individuals' responses, especially those of cancer patients themselves (Glaser and Strauss, 1965; Kuhler-Ross, 1969; McIntosh, 1977; Hesky, 1987). From these writings, it can be seen what it is like to live with cancer. However, most of these studies concentrate on western society and there is little in the way of documented studies concerning the perspectives of patients living with cancer in the non-western world.

As most studies concerning the experience of cancer have been conducted with patient populations in western society, the generalisations of those findings to eastern populations is probably not warranted (Long and Long, 1982; Ohnuki-Tierney, 1984; Chrisman, 1991). Therefore, this field of study will focus on experiences as perceived by Thai cancer patients, who have a vastly different cultural background than those at the centre of most of the documented studies available today.

As a Thai nurse, having the same cultural and linguistic background as those whose experiences will form the core of the intended study, the researcher believes that this investigation will provide knowledge about cancer from the Thai patient's point of view. This knowledge will enhance the ability of Thai health care providers to understand patients' problems within their Thai socio-cultural setting. Failure to achieve this understanding may result in frustration for both patients and providers. At worst, the patients' social problems may remain unsolved.

In every society, peoples' behaviour is determined by their cultural rules. This is decidedly so in the medical context where those rules not only identify who is to be considered ill, but also, how the ill person and those around them are expected to behave (Kleinman, Eisenberg and Good, 1978). Although being ill or suffering from disease is an undeniable aspect of the human condition, suffering from cancer illness in particular, evokes strong emotional responses which are culturally channelled into symbolic images and behaviour (Chrisman, 1991).
This study then, in attempting to explain the cultural responses to cancer illness by Thai patients, not only aims at providing information for Thai health care providers, in dealing with patients who bring their own beliefs and experiences with them into a medical setting, but also, to provide an interpretation of Thai culture and society based on an examination of the health-related activities and beliefs of the Thai.

It attempts to identify those areas of concern by focusing on the patients, who whilst going through experiences of suffering from cancer, consisting of their beliefs as well as their concepts of health and illness related to their own illness, have stepped out of their world into a very rigid, medically oriented world, a world which is controlled by people who do not necessarily share those same beliefs and concepts.

Background of the Study

The researcher's involvement in cancer nursing began in 1977 when assigned to work as a staff nurse in the female surgical ward of Siam Hospital, a ward in which at least half of those under care were cancer patients. An interest in cancer nursing emerged from the everyday practice with these patients which developed to an awareness that there were more questions than answers when confronted with requests from cancer patients, who wished to know more about their diagnosis and/or prognosis.

Personal limitations in providing an informative account of patients' illness came (partly) from the practice of withholding the true diagnosis from patients in Thai society. Therefore, when asked by the patients about their diagnosis, the only advice that could be given, was for them to ask their doctor, or at times, just ignore their questions. Patients, after receiving negative responses from the doctors, would sometimes press for an answer which was countered by avoiding any contact that was not directly related to that of providing care. This led to feelings of frustration and a sense of inadequacy at not being able to help the patient further at a time, which for them, held a great deal of anxiety and uncertainty.

Through observing the care being provided, the researcher was confronted with a puzzling situation concerning those suffering from cancer, in that there was no specialized care given to those admitted as cancer patients, whereas all available literature (from studies conducted in western societies), suggested that there should be some degree of specialized care available.
Although the nursing care at that time was generally considered to be adequate, it was by no means, specialized. After again referring to text books based on western experiences, and conferring with other health care providers who had studied within western health care systems, the researcher came to believe that the approach taken towards caring for cancer patients, by most Thai health care providers, was inadequate.

The researcher's interest grew to where, in 1986, a proposal to study at the Institute of Cancer Research, Royal Marsden Hospital, London, was accepted. During the nine months course study period, it was found that although the cancer treatment and associated technology was similar to that found in Thailand, it was evident that the supportive care given to the patients at Royal Marsden Hospital, was far more advanced.

It was intended that the researcher would apply the knowledge gained abroad to the daily care of Thai cancer patients. However, the prevailing hospital system frustrated any attempts to implement that knowledge. Then as now, the code of medical ethics laid down by doctors on a personal belief basis, not only dictated the type of care provided, but also, whether or not the patient was told the diagnosis.

At that time, the researcher began to debate with doctors on the question of "openness" and supported her argument by referring to the recent experiences at Royal Marsden Hospital, as well as the existing research studies. Unfortunately, most studies referred to research conducted in western societies which the doctors rejected as not being appropriate within the Thai cultural setting, insisting that Thai cancer patients could not cope with the true diagnosis.

From listening to the work-place conversations, the researcher became aware that there were two schools of thought within the doctor/nursing ranks, both based on the individual's beliefs which stemmed from their knowledge and past experience in dealing with cancer patients. One line of argument insisted that the western approach toward cancer patients could not be applied because of cultural, social and religious differences, whilst the other suggested that those same approaches could be successfully adapted to suit Thai patients. It became clear, from these professional differences of opinion, that neither group really understood the view of cancer as perceived by Thai patients themselves.
Debate on this issue was not only confined to the doctors and nurses within the workplace but was also to be found in copious amounts of existing literature coming from a wide variety of sources. Those published accounts however, would invariably refer to the providers point of view on how they should approach the question of telling the truth, which was in stark contrast to the almost negligible amount of information concerning the patients own views on informed diagnoses. It seemed therefore, that an essential element in providing appropriate patient care was missing. As well, it had become overly apparent that the question "How do Thai cancer patients perceive their illness?" needed to be addressed.

Cancer and Thai Society

In Thai society, cancer is viewed as a fatal disease and is one of the major health problems that besets the Kingdom of Thailand where it is generally accepted that this disease, with its high mortality rate, a lengthy and costly treatment programme, as well as the high degree of severity in the way it afflicts its victims, makes it one of the most difficult diseases yet confronted by those in the forefront of the battle against human illness.

During the past twenty years, studies of the leading causes of death among the people of Thailand clearly indicate that cancer has now emerged as a significant disease which tends to kill an increasing number of Thai people. Statistical evidence from a report published by Division of Health Statistics (1970), showed that in 1966, cancer was ranked eighth amongst the major causes of death with a mortality rate of 11.5 per 100,000 head of population. From a report published by the same source (1989), it was shown that by that year (1989) the mortality rate from cancer had risen to 36.5 per 100,000 head of population and ranked second only to that of heart disease as the major cause of death. Yet these figures have a metaphorical significance beyond what the statistical evidence alone would suggest.

With these figures in hand, the Thai government, in their efforts to reduce cancer morbidity and mortality rates that were highlighted in a steady stream of reports similar to those mentioned above, embarked on a programme of promoting the prevention and the early detection of cancer, as well as encouraging research studies of various subjects relating to cancer by individuals and professional bodies involved in those areas of concern.
It is unfortunate however, that although the government’s original plan was to provide these services on a national basis, it has become evident that they are centralized in the major cities and university hospitals throughout Thailand (Unhanand, 1984). This means, that for those people living in the more remote rural areas, it is necessary for them to travel great distances, spend valuable time away from their employ and incur a financial burden in order to benefit from those services.

Remembering that the population spread of Thailand shows that the majority of people live in the rural areas, it would seem that they are placed at a distinct disadvantage because of their geographic location. This problem has been recognized by the government which has embarked on a five year health development plan (1989-1993) to decentralize those services concerned with the prevention and control of cancer to the provincial areas. Because of the limited amount of funds available and the shortage of trained personnel, the government has only been successful in establishing another six centres for the early detection and management of cancer treatment (Phanthumachinda and Sontipong, 1989).

This project, which was into its second year during the time spent in the field for this research study, fell short of providing an effective service for the greater majority of the rural population. The facilities already in place however, were successful in increasing the number of cancer patients surviving within Thai rural society. This meant, that with the increase in the number of survivors, came the inherent increase in demands for hospitalization and with the limited resources that were available, further strain was placed on the already overcrowded and overworked treatment facilities.

A more complex side to the problem became evident at that time, which supported earlier studies, in that there was evidence to show that many cancer patients from rural areas did not use the available health resources for early detection, but rather, reported to those centres only when the cancer disease had progressed into a later stage (Sutnick, Lynch and Miller, 1984). In these cases, the patients were then referred to one of the centrally located treatment centres for advanced treatment, thus negating the effectiveness of the early detection programmes. This delay in seeking treatment was indeed a major concern to those involved with the problems related to the management of cancer in the more remote regions of rural Thailand (Pitakspraiwan, Phanthumachinda and Woramontri, 1988).
It was a common occurrence for the health care provider working in the major treatment centres of Thailand, to see the patients arrive for treatment, far too late into the course of their illness and when fewer therapeutic options were available to them. This was especially so for those patients from the rural areas. From articles published on this matter (Sutnick, et al. 1984; Unhanand, 1984; Phanthumachinda and Sontipong, 1989), it has been clearly identified that the problem areas were the lack of treatment facilities in those rural areas as well as the missed or incorrect diagnosis of their cancer illness. As well, it has been noted that in most cases, the patients are considered the blameworthy party and to be responsible for their own late involvement in the cancer treatment programmes.

Patients were usually labelled by the health care providers as being naive and easily deceived in having wasted their time and money in seeking help from maw tuan (quacks, traditional healers). It was found however, that the patients in most cases, to have not only wasted those precious commodities, but rather, lost everything, which for some was their life savings, whilst others were forced into bankruptcy. By the time the patients had finally decided to seek help through conventional treatment, they were without the monetary means to afford the travel to the treatment centres.

Also, patients were accused of taking too long in making the decision to receive conventional treatment following the suggestions given by their local doctors. It was also found that some patients, even after they had decided to undergo treatment as advised by their doctor, were too attached to their homes, their fields or in the management of their own private businesses, to find the time to act on the advice of those doctors. As well, public misconceptions that conventional cancer treatment, especially radiotherapy, as not being effective against cancer, was recognised as another factor that prevented the patients seeking treatment in the early stage.

In considering the problems in cancer management and cancer care existing in Thailand at the time of this study, particularly in those areas of delay in the seeking of treatment and public health education, suggestions were made that emphasis should be placed on the early detection of cancer and its early treatment, as well as initiating an education programme designed to correct public misconceptions regarding cancer treatment. It was also suggested, that serious efforts should be made to eradicate the traditional healers who purport to be able treat all forms of cancer (Unhanand, 1984).
With such a wide range of suggestions put forward concerning problems relating to the management of cancer, it was disheartening to find that no details were given as to how these suggestions should be implemented. Furthermore, the stance taken in giving these suggestions, appear to be exclusively from the providers viewpoint and there was little in the way of recognizing the patient as having a legitimate point of view.

Statement of the Questions

As in other countries, cancer and its negative image was to be found in Thailand. As well, the practice of withholding the true diagnosis from the patients in Thai society has meant that there was very little known about patients own feelings on cancer and its treatment, as there has been no venue for health care providers to discuss this with the patients. As a result of this lack of knowledge, this researcher began to wonder whether or not the existing problems of cancer in Thai society could ever be managed successfully if we continue to orient our care programmes solely from a providers point of view.

For this researcher, questions such as, Can we successfully establish a viable health education programme, without fully understanding those people who are to be recipients of the care we wish to provide?; and Can we really eradicate traditional healers as a health care option, available not only for the poor, but also for those people who think that traditional ways are of significant importance to their own well-being, and which are closely linked to cultural and religious beliefs? It was the researcher's strong belief, that by understanding the patients behaviour, was to identify the crux of the existing problems and was therefore, an essential element in solving those problems. That is, if we were able to understand why the patients behave as they do, we would then be able to correctly assess the nature of the problem.

It has been the experience of this researcher, having been involved in providing nursing care to cancer patients for more than ten years, that Thai cancer patients are rather unique in their response to illness, as they appear to be accepting of any life situation they may encounter. Usually, Thai individuals who suffer pain from a life threatening disease are consoled by the thought that they alone, must bear the responsibility for their suffering. Essentially, this belief comes from the philosophical foundations of Buddhism, in that the pains and pleasures which a person experiences are the results of his or her own actions in a previous life (Mathews and Nagata, 1986). This belief is likely to be a key factor in understanding Thai cancer patients' response to illness.
From this ingrained sense of fatalism, Thai patients tend not only to accept suffering, but also try to live with the suffering by remaining in good spirits in the hope that "debts" of a past life, have been paid (Wijeyewardene, 1986). This strong Thai belief, being part of their Buddhist heritage, is that life is only one chapter in a book of lives and that the way one acts in this present life, directly affects the character of the next life and even the form one will adopt in that life. Therefore, if one is 'bad' one can expect to be punished by returning in the next life marked by ugliness, poverty, illness or even as a lower form of life (Mathews and Nagata, 1986). To most Thai people, this is the only way for them to repay the debt from a previous life, and hopefully, it will enable them to progress to the next life, free of those ailments that beset them in the present life.

There was no empirical study concerning cultural influences on the experience of cancer from the Thai cancer patient's point of view. Therefore, it is the strong belief of this researcher, that if Thai cancer patients can cope because of their outlook on life, whether or not they know the true diagnosis, and if health care providers can identify and acknowledge this as a valid means of the Thai patients acceptance of their disease, then communication and treatment plans will be more congruent between patients and providers. And so, with this point in mind, this researcher attempted to understand more about the meaning and experience of cancer as perceived by Thai cancer patients.

Structure of the Thesis

This study is reported in eleven chapters. Chapter two is a literature review and contains sections on cancer illness and its associated problems within Thai society; the status of cancer nursing and cancer research in Thailand; and the findings of previous cancer studies and the research methods used including both quantitative and qualitative approaches. This chapter also illustrates the relationship between nurse and patient, as well as stressing the importance of understanding the cancer experience from the patient's point of view. As well, it introduces the ethnographic method used in this study along with the statement of the questions concerning the study. Details of the ethnographic study are presented in chapter three. Methods used in collecting data, the ethical considerations involved with the collection, as well as the methods used in the analysis of that data are also presented in Chapter three.
Chapter four discusses the experience of conducting research in both the shelter and the treatment centre settings, and includes the experiences of gaining entrance, seeking acceptance, and establishing rapport. Chapters five to ten contain the descriptive results of the study on Thai cancer patients, whilst Chapter five presents the patients' health seeking processes. Chapter six contains an outline of the shelter setting, as well as providing a descriptive account of the staff and patients within that setting. Chapter seven discusses the functions of the treatment setting, as well as profiling the treatment centre staff and their tasks.

Chapter eight focuses on the life experiences of the patients whilst undergoing treatments. Chapter nine focuses on the impact of cancer illness and its treatments on the patients, whilst Chapter ten looks at the patients' coping mechanisms and the management of their problems. Chapter eleven puts forward the conclusions drawn from this study as well as discussing the implications of the findings in relation to Thai cancer patient care, nursing education and nursing research.
CHAPTER 2

LITERATURE REVIEW

Introduction

In this chapter, existing publications on cancer nursing studies, and other related studies, have been reviewed in order to know more about the current, new trends, and advances in the overall knowledge of cancer care. Literature on the ways of conducting those studies was also reviewed, which eventually led to the selection of an ethnographic approach as being best suited to study the experiences of Thai cancer patients and to solve the ethical dilemma surrounding a study of this nature in a Thai cultural setting. As well, the nature of nursing as a practice discipline was reviewed, which in turn highlights the importance for nurses to understand patients' illness and experiences, and which was of central concern to this enquiry.

Cancer in Thailand and its Problems

Recent data suggests that cancer kills more Thai people than any other disease with the exception of heart disease, but unlike heart disease, the number of cancer cases continues to rise each year. The mortality from cancer among the country's 55 million people has been steadily increasing to where in 1989, figures released in public health statistics indicated, that it accounted for more than eight percent of all deaths (Division of Health Statistics, 1989). The age bracket of the majority of sufferers whose deaths were attributed to cancer ranged, from 45 to 54 years where the female to male death ratio was 1:0.9 with the high being that of women (Phanthumachinda and Sontipong, 1989).

The most frequently affected organs in males were the liver, lungs, oral cavity, colon and stomach, whilst for females, it was found that the cervix, breasts, oral cavity, liver and colon were most frequently affected. It was also found that there has been an alarming increase in liver cancer, especially among males. It is believed that this increase in liver cancer among Thai males, may be associated with the prevalence of hepatitis B and the consumption of alfatoxin contaminated food (Unhanand, 1984).
Conversely, the number of patients who suffered from cancer of the oral cavity and cervix was seen as having declined slightly. It has been suggested that the changing incidence of the various types of cancer may be associated with changes in social development (Phanthumachinda and Sontipong, 1989).

In reports published by The National Cancer Institute (1971-1982), evidence was presented that showed the incidence of the various types of cancer, differed from one geographical area of Thailand to another. The statistical evidence from those reports showed that in the central and northern areas of Thailand, cervical cancer and lung cancer were the most commonly found types, whilst liver cancer and cervical cancer were predominant in the northern and eastern regions with cervical cancer and cancer of the oral cavity the most frequently found types in the southern parts of the nation.

Thailand, like most western countries during the past decade, showed a trend toward longer life spans and increased survival ratios, which has dramatically changed the scenario following a cancer diagnosis. As well, the recent development of new therapies, such as, radical surgical techniques; radiotherapy; and chemotherapy, have transformed cancer from what was a rapidly fatal group of diseases to what is now classified as a chronic illness of the 80's and 90's (Woods et al., 1989). Along with the increasing number of cancer patients surviving within society, there is the inherent increase in demands for, hospitalization for diagnosis; the various forms of initial treatment; treatment of metastases; recurrences; complications or advanced disease; and for care in the terminal phase (Germain, 1979).

In Thailand, the problem was compounded further, as the number of beds for cancer patients were limited, with treatment such as radiotherapy and chemotherapy usually provided on an outpatient basis. Moreover, when the treatment required was of a more technical nature, such as radiotherapy, greater stress was placed on an already overtaxed system as that type of treatment was available only in the cancer institute or university hospitals located in the few major cities. That is, in Bangkok, the nation's capital, there were four university hospitals and a National Cancer Institute providing cancer radiotherapy services. Similar services had been established in the provinces of Chiangmai, Khon Kaen, and Songkhla, being sited in the three university hospitals located in the major cities (with the same name) of those provinces (Unhanand, 1984).
The situation as it existed then, was that individuals from rural areas, who had limited or no access to local radiation treatment, had to leave their families and travel to their nearest treatment centre in order to receive such treatment (Hanucharurnkul, 1988). However, not many patients were lucky enough to be able to make use of the limited facilities which were available in the provinces. With most patients having to leave their families and homes to make the long journey to Bangkok, they were obliged to seek shelter with relatives, friends, or find refuge in Buddhist temples whilst some were allocated to a Cancer Hostel, which was made available specifically for those patients who were to receive treatment during that critical period and for various reasons, could not find shelter elsewhere (Thai Cancer Society, 1987). However, it was often found that those patients who were fortunate enough to be able to afford the long journey to available treatment centres, came too late for any kind of treatment to be of help (Unhanand, 1984).

The situation, in which we see cancer patients making their first visit to the doctor with their illness in its latter stages, was common in Thailand, as it was throughout other third world countries (Sutnick et al., 1984). As well, patients arriving too late for the treatment to have any chance of success was another significant problem facing those engaged in the fight against cancer in Thailand at that time (Pitakspraiwan et al., 1988). Although several types of cancer were known to respond very well to certain kinds of treatment, it was only if the disease was caught in its early stages, that any chance was given for a successful outcome (Unhanand, 1984).

For the late stage cancer patients, it was not only a case of the available treatment being less effective, the high costs involved in treatment management also had to be considered. As well, patients arriving in the late stage was one of the contributing factors to the high mortality rate among Thai cancer suffers when compared with patients with the same cancer diagnosis in the western world (Pitakspraiwan, et al., 1988).

The conclusions drawn at that time, of the causes relating to the late seeking of treatment by Thai cancer patients, were identified as, having no health resources which could be accessed easily by the patients; being unaware of the fact that they had cancer; did not know of the severity of the disease; had misconceptions about cancer treatment from listening to uninformed lay persons; and poverty, which was claimed as being the most frequent cause (Sutnick, et al, 1984; Unhanand, 1984; Phanthumachinda and Sontipong, 1989).
The prevalence of cancer disease in the years leading up to this study, had seen it ranked second among the major causes of death and was accorded high priority in terms of cancer management. In 1987, the Thai government, in realizing the importance of the prevention of cancer, focussed their efforts on early diagnosis and embarked on a five year project which was scheduled to operate from 1989 to 1993, with emphasis on cancer prevention and control (Pitakspraiwan, et al., 1988). This project entailed the setting up of a further six facilities for the early diagnosis and treatment of patients within provincial areas. The objective of this project, was to decentralize health resources to the rural areas for the benefit of cancer patients living in those areas, and where they would be given direct access to modern diagnostic and treatment facilities. As well, patients would be spared the expenses incurred in the long journey to those treatment centres located in Bangkok or the provincial capitals. The expectations of this project were for cancer patients to have easy access to diagnostic and treatment facilities during the early stage of their disease. As a consequence, cancer was diagnosed early which resulted in patients being given a better chance for survival through the timely administration of therapeutic treatment, which of course, had the desired effect of finally reducing the mortality rates from cancer.

Although this project was already into its second year during the time spent gathering data for this research study, it was evident that those optimistic expectations had not yet been realized. This point was evident, as there were still a large number of cancer patients presenting themselves for treatment at hospitals in very advanced stages. As a consequence, the number of terminal patients increased markedly, with the ranks being swelled by those patients who came to the hospital in the late stages of their disease, as well as the patients who were surviving longer, due to the advances made in treatment technology. As was the case in many developing countries, Thailand could not afford the high cost oriented policies of richer nations, where there is an integration of continuing care such as hospice care and palliative care, into all stages of cancer treatment. The lack of this kind of care in Thailand, has seen that terminal cancer patients, who were to be found in the overcrowded institutions and hospitals throughout the country, were indeed suffering needlessly.

**Cancer Nursing in Thailand**

In Thailand, content on cancer nursing care had been included in nursing programmes since the early 1900s. In those early programmes the content of cancer nursing appeared under the subject heading of pathology as well as general nursing care. The primary concern of those involved in cancer nursing was for the provision of bedside
care and comfort measures for surgical patients. Although the nursing curriculum was reviewed and developed many times over the following years, cancer nursing care was not presented as a specific content in any resulting new programme. It was not until 1978, when the Faculty of Nursing, Mahidol University, developed the Bachelor of Nursing (continuing programme), that content on cancer nursing care was first presented as a separate subject. It was also at that time, that content was first included in the Masters Degree programme of Mahidol University. However, very little time in the overall nursing curriculum was devoted to what would be regarded today, as an adequate level of content.

More recently, the faculty of nursing began to integrate content and electives into cancer nursing at the undergraduate level. However, this fundamental knowledge was seen to be inadequate in the preparation of those who were to become involved in cancer nursing. As well, the requirement for cancer nursing care to be regarded as a speciality, had increased following the rapid growth of interest in the field of cancer. The Faculty of Nursing therefore, established the first cancer nursing course in 1990 with aims of preparing the registered nurse to deliver competent cancer nursing care. There was however, no further or follow-up course in place at that time aimed at allowing those nurses to become specialists in cancer nursing care.

The attempt at the development of the cancer nursing specialist, had not only been confined to the field of nursing education, as the need for specialty in cancer nursing care had also evolved in the clinical area because of the extensive and specific body of knowledge necessary to give safe and thorough care to specific cancer patients. Earlier attempts to provide training for those involved in clinical care, met with some success, with a five day short course on cancer nursing care for registered nurses being introduced in 1975. Although the course was conducted just once a year using the facilities of Siriraj Hospital and sponsored by the Thai Cancer Society, it was, unfortunately, terminated after only four years due to the lack of funds and a shortage of qualified personnel to run the course. Similar courses were later conducted by other institutions in the Bangkok area, which included a course run by the Thai National Cancer Institute. These attempts to educate nurses in cancer care however, were inconsistent and lacked any form of continuity.
Cancer Research in Thailand

Though there were a large number of published research findings on cancer in Thailand, most of the material dealt with basic research into etiology of cancer or its treatment. Cancer nursing literature dealt with reports of nursing care procedures or programmes for cancer patients in the hospital setting. Although nursing research in oncology nursing and cancer care was still in its infancy in Thailand, it was gratifying to see that more studies were being undertaken in those study areas by nurses at masters degree level. However, most studies were based on theories and methodologies of cancer research which had been conducted in western countries. In spite of there being many Thai nurses who have realized that nursing in Thailand should not continue to uncritically accept western-oriented theories and methodologies, up to the time of this study, there had not been any development in those fields which were uniquely their own.

As well, those studies that have been carried out in the field of nursing research, have been conducted using quantitative research methods. This is because Thai nurses have been taught to value and use quantitative types of research and statistical methods to investigate the research question. There has been no preparation of potential nurse-researchers in the use of qualitative research methods which has rich and promising potential for nurses to generate their own base of knowledge (Leininger, 1985).

Review of Cancer Studies

Although, the purpose of this study was to understand the lived experiences of the Thai cancer patients within their own cultural setting, the lack of any form of existing literature concerned with the study of Thai cancer patients, precluded any help that would be gained by reviewing such literature. Initially, it was keenly felt that without any form of research material from one's own culture to guide or to gauge one's progress through the formative stages of this research study, a crucial element of this, or any such study, was missing. It was therefore, necessary to review a great deal of literature on studies done within other cultural settings in order to learn how the study was conducted, the methodology used as well the research findings.

STUDIES RELATED TO THE PROBLEMS SPECIFIC TO CANCER

There are two important aspects that appear to set cancer apart from most other illnesses and influences how patients respond to their illness. Firstly, there is likely to
be a profound sense of diminished personal control (Abrams, 1966; Silberfarb and Greer, 1982), where diagnosis of cancer along with associated treatment protocols can readily diminish an individual's sense of mastery (Brockopp, Hayko, Davenport and Winscott, 1989). As well, treatment such as surgery, chemotherapy, or radiotherapy cannot be performed by the patients themselves. Also, they are often referred to an unknown medical specialist and admitted to a treatment centre where their privacy is removed, seemingly in the same manner as the disappearance of their personal belongings. Furthermore, there is a distinct lack of understanding regarding future events that directly concern them, with a tendency to become reliant on strangers for their daily requirements (Donovan and Girton, 1984), with goals and future life plans no longer theirs to manage, but rather, in the hands of others (Abrams, 1966). They have in fact, lost control over a situation that could severely limit future attempts to acquire a sense of mastery and control that patients can achieve over their illness (Brockopp et al., 1989).

The second important feature which sets cancer apart from other illnesses and influences patient responses, is that cancer is a disease in which the physician shows uncertainty as to the outcome (McIntosh, 1977; Silberfarb and Greer, 1982). Usually, doctors cannot be certain that the disease in question, is in fact cancer, until an investigation, usually a biopsy, has been carried out, whilst the outcome of the illness can be difficult to predict. Moreover, even when the diagnosis is confirmed as cancer, doctors are seldom certain of patient prognosis because of the distinct possibility of a distant metastasis or of recurrence without warning.

These two factors, lack of personal control and that of uncertainty are central themes that set cancer apart from other illnesses and influence how patients cope with the disease (Donovan and Girton, 1984), as well as how patients, families and physicians communicate (Silberfarb and Greer, 1982)

STUDIES RELATED TO PATIENTS' COPING WITH CANCER

To be diagnosed as having cancer is a very stressful experience (Wool and Goldberg, 1986) and for some, the thought of dying has become "part of their new and final social identity." (Kellehear, 1990, p. 65) Not only has the future now become unpredictable, an element of uncertainty also exists, as even with the best possible treatment, the disease may still spread throughout the body causing pain and/or death. Furthermore, the treatment for cancer can kill, cause pain, change body image and interrupt normal
life activities, which in themselves are extremely stressful (Silberfarb and Greer 1982). In order to understand patients' experiences and their responses to this stressful disease, "psychological considerations are of great importance" (Gotay, 1984, p. 605).

Recent years have seen many studies relating to psychological and social responses of cancer patients. Among these, Morris, Greer and White (1977) used structured interviews and questionnaires to investigate 69 breast cancer patients. From this enquiry, it was found that regardless of whether or not they had been specifically told their diagnosis, they responded to the illness in ways that were classified into five principal categories, these being:

a. Denial, - actively rejects evidence of diagnosis and is guarded and restrictive in response;

b. Fighting spirit, - shows a hopeful attitude in seeking more information and expressing interest concerning positive chances;

c. Stoic acceptance, - accepts diagnosis with no excessive concern for illness;

d. Anxious / Depressed acceptance, - reacts with excessive anxiety or depression and pessimistic in outlook whilst carrying out normal activities; and

e. Helpless / Hopeless, - overwhelmed by the diagnosis.

Gotay (1984) investigated coping mechanisms in patients with early state cervical cancer and advanced state breast or gynaecological cancer. Her data was obtained through personal interviews of 112 patients, in which it was found, that the most frequently mentioned initial coping reactions in the early stage group (shown here in order of ranking) were taking firm action; seeking more information; and finding something favourable about the situation. For the advanced stage group, the responses of seeking more information; finding something favourable about the situation; seeking direction from authority; and avoidance and denial, were the most frequently found.

Other findings relating to psychological and social response can be found in the study by Mages, Castro, Fobair, Hall, Harrison, Mendelsohn, and Wolfson (1981), in which 66 cancer patients of varying ages and diagnoses were interviewed to determine the nature of their response to cancer. These subjects were separated into two groups with one group having recently received treatment for their disease and the other consisting of long term survivors. From those interviews, it was found that there were three main responses, with the largest group of respondents doing well, a minority were coping satisfactorily with progressive disease, whilst a small number reflected a lack of adjustment to their illness. Some degree of denial had been seen in the study, although
in an earlier study by Morris et al. (1977), little evidence of denial was found. The study by Gotay (1984), indicated similar findings, in that none of the 42 cancer patients in an early stage group, cited denial as a coping strategy, there were however, some within the advanced stage group who did. Silberfarb and Greer (1982) showed that denial is a common psychological response and is a protective mechanism which gives the patient time to adjust to a life threatening disease.

In the study by Sanders and Kardinal (1977) it was reported that denial is one of the common adjustment styles by which patients attempt to cope with their illness. These findings came from non-structured interviews with six adult acute leukemia patients who were in clinical remission and from which it was found that all identified denial as a coping mechanism which became manifest in a number of ways. The means by which cancer patients express their denial is clearly identified in the study of Wool and Goldberg (1986) in which they found, after interviewing 15 cancer patients who delayed in seeking treatment, that there were four types of denial presented by those patients. These were, denial of the physical manifestations of the illness; the diagnosis; the implications of the illness; and the effect.

In general, the report tended to support the assumption that denial was an important defense mechanism for the emotional adjustment to the stress of cancer (Silberfarb and Greer, 1982; Donovan and Girton, 1984). However, there were controversial findings concerning denial being seen as either a positive or negative response influence on adaptation to cancer (Wool and Goldberg, 1986; Frank-Stromborg, 1989).

There were some cross-cultural studies focussing on cancer patients perceptions of their illness. Three studies concerning attitudes toward cancer, were conducted in different cultural settings, notably, Switzerland (Kesselring, Dodd, Lindsey and Strauss, 1986); Egypt (Dodd, Ahmed, Piper and Lindsey, 1985a); and Taiwan (Dodd, Chen, Piper and Lindsey, 1985b). These three studies used a questionnaire on attitudes to cancer and its treatment which was translated into the native language. Using an investigator who was from that culture and who was fluent in both English and the native tongue, brief notes were taken on participants' responses during interviews. Immediately after the interviews, the investigator expanded on those notes. The interview questions were described and summarized individually. These questions, consisting of five major issues were: 1. What do you think caused your cancer?; 2. What does having cancer mean to you?; 3. What does your having cancer mean to your family?; 4. What does your treatment mean to you?; and 5. What does your treatment mean to your family?
The findings of the study showed that there were five patterns of expression to ascribe meaning to the illness. These patterns were, dying; giving up; resigning; accepting; and integrating, and were related to their attitudes, causations, time since diagnosis, and relationship to others.

When comparing the findings within the three cultures in relation to their perception of their illness, the following points became apparent. Those Taiwanese with more formal education, perceived their illness as "severe and life threatening" and held "little hope" which contrasted with those having little or no formal education who found their illness to be "mild" and "causing little worry." For most Egyptians, it was "a painful experience" and "stressful situation" with others having feelings of "insecurity and depression." To some, it was a "long term illness" whilst others held "feelings of guilt." The Swiss held the same perceptions as both Taiwanese and Egyptian sufferers, with the one exception of not including "mild and of little worry."

Taken together, these studies not only illustrated the basic response of cancer patients, but also showed the wide variation in research findings. As well, numerous recommendations were made from the results of these studies. The most significant of these in relation to the present study, was that the researchers agreed that information concerning beliefs and attitudes, was vital in providing culture-specific cancer care.

STUDIES RELATED TO FACTORS CONCERNING PATIENT'S RESPONSE

It is clear, that in order to understand the emotional reactions of cancer patients, it is necessary to be able to describe the patterns of their response to cancer. As well, it is most valuable to be able to identify the factors contributing to their responses when considering the outcome of those patterns.

The study by Morris et al. (1977) found that there were changes and adjustment of responses to the diagnosis of cancer. After documenting the patterns of response of breast cancer patients with elapsed time since surgery ranging from 3 to 24 months, it was found that there was a change in the frequency of the different responses. The formation of changes to the patterns of adaptation were also found in the study by Mages, et.al. (1981) where it was noted that three or four months after diagnosis the patterns of adaptation tended to persist and did not change unless a marked alteration in the patient's condition occurred.
It is of interest to note, that cancer patients do not persist with initial patterns of response to cancer, but rather, tend to change and adapt over a period of time. There are many studies which have attempted to investigate the factors that relate to these changes.

Silberfarb and Greer (1986) mentioned that psychological and organic-demographic were the major factors which modify the patterns of patient response. These factors include, the patient's premorbid psychological development; cultural characteristics; the quality and quantity of emotional support; prior experience with illness; and the setting in which cancer develops. The organic-demographic factor refers to age, sex, profession, stage of career, cell type and stage of cancer, prognosis, and physical impairment related to illness and its treatment. Furthermore, Mages et al. (1981), found that there were three sets of variables related to adaptation in cancer patients, these were, the medical situation referring to the severity of illness and prognosis; previous psychological stability; and the network of social support.

Some studies have shown interest in specific aspects related to patient response as noted in the findings of Hinds and Martin (1988). Within this study, Hinds and Martin shared the view that hopefulness was critically important for individuals to cope with cancer. Their study was conducted using the grounded theory method to explore the process of achieving hopefulness in adolescents with cancer. This study found that feeling hopeful along with personal competence (commitment to treatment, adaptation to symptoms and taking care of problems) helped the patients adapt to disease and treatment. Moreover, it was found that the adolescents' adaptation outcomes were "self-focused" and not environment-focused, again reflecting the adolescents' belief that personal control of the disease does not exist. The study by Hinds and Martin (1988) supports the concept of hopefulness being essential for cancer patients, that is, feeling hopeful is critically important for individuals diagnosed as having cancer, not only in adult cancer patients (Donovan and Girton, 1984) but also in adolescents with cancer.

Brockopp et al. (1989) investigated the relationship between levels of perceived personal control and the need for hope and information. Questionnaires were used to examine 56 adult cancer patients. The study found that the relationship between the patients' hopes of future pleasurable experiences; desire to share learned illness experiences with others; and personal control, do not support the notion that an individual's sense of personal control is strongly influenced by the needs for hope and
information. This research suggests that giving information and facilitating hopefulness as relating to the need to increase control, is not warranted unless data from the patient clearly defines the relationship.

Findings similar to those found in the above mentioned studies on the giving of information to cancer patients, were noted in a study conducted by McIntosh (1977) in which participant observation and interviews were the main methods used for data collection. In that study, eighty patients were interviewed over a period of six months. Altogether, one year was spent in observing the interactions of those involved. The subjects in that study had not been informed of their diagnoses, although it was found that the majority of patients knew or suspected that they had cancer. Therefore, the patients were subjected to a great deal of uncertainty about the nature and severity of their illness.

McIntosh (1977) hypothesized that patients would attempt to cope with uncertainty by seeking information about their condition. It was found however, that only a small minority of patients sought to find out the truth about their condition with many of them not wanting confirmation of their diagnosis. In fact, they preferred the uncertainty of not knowing to that of knowing as it was precisely that uncertainty which afforded them hope. In this situation, they managed their uncertainty by seeking only that information which confirmed that they might not have cancer. Although these two studies differed in the way in which the research was conducted, a similar finding emerged, in that information is not always of benefit to patients.

Different findings can be found in the study by Wortman and Dunkel-Schetter (1979) in which they reviewed the many well-controlled experimental investigations concerning information and found that there were a large number of those investigations which showed that patients who received information about what to expect prior to treatment, coped better than uninformed patients. The suggestion from their study was that giving information to cancer patients would reduce the level of patient distress. As can be seen, there is controversy between the different findings on the giving of information to cancer patients, as well as there being no standardised approach regarding this topic. However, Donovan and Girton (1984, p.49) suggested that "The only guides are the individual's questions and his responses to each additional piece of information provided."
While the attitude of giving information to cancer patients is wholly legal and more open in nature in most western societies (Veatch and Tai, 1980; Silberfarb and Greer, 1982), other societies still withhold information from the patient as mentioned in the writings on the Australian-Greek community (Kanitsaki, 1989) and in the studies of Japanese cancer patients (Long and Long, 1982; Ohnuki-Tierney, 1984).

As found in the study by Long and Long (1982), Japanese doctors consider it unethical to reveal a diagnosis of a potentially life threatening disease to their patients, but rather, found it more acceptable to reassure them of eventual recovery. As well, the patients themselves, in compliance with family responses, play a specific role in deception, although they may suspect the truth in the matter.

From the literature reviewed, it can be concluded that patients exhibit a range of responses to cancer whether or not they were told the diagnosis. The exact responses of an individual to cancer are far from predictable and depend on many interpersonal, intrapersonal and environmental factors. In other words, patients create the meaning of cancer through the constant interaction between themselves and their social surroundings (Blumer, 1969).

**Qualitative and Quantitative Research Approaches**

There have been copious amounts of cancer research studies thus far conducted by a virtual army of researchers who have employed an equally impressive number of ways and styles in the conduct of those studies. It could be concluded however, regardless of styles or ways, that on a very broad scale and in a more traditional sense, people have been studied either in terms of numbers or words. This infer that where people have been studied as numbers, a quantitative approach to information collection and analysis has been used. That is, researchers selected a limited number of variables around which specified data categories and items were identified. These were then merged into a structured, precoded interview questionnaire. After collecting the data from a group of patients, researchers then proceeded to code the answers either manually or with the aid of a computer and began to correlate and cross-tabulate data. This then, enabled the researcher to find patterns in patients responses and by extension, in the decisions and behaviour of the people under study.

On the other hand, the approach which is qualitative in nature, rests on the collection of subjective information, as given by either the researcher or subject. Data of this type is in the form of words rather than numbers or statistics where the data sources vary
immensely and is collected in a variety of ways which includes conversations, participant observation with informal interviewing, and in-depth interviews such as life histories. Data are processed, even before they are used, in the form of recordings, notes and transcriptions. One aim of qualitative studies, and the data upon which they rest, is to be cumulative. As Miles and Huberman aptly state:

Words, especially when they are organized into incidents or stories, have a concrete, vivid, meaningful flavor that often proves far more convincing to a reader—another researcher, a policy-maker, a practitioner—than pages of numbers (Miles and Huberman, 1984, p.15).

Whilst these two data collection strategies have customarily been separate, it has been seen that in recent times a greater number of researchers involved in traditionally quantitative fields have become actively interested in using qualitative techniques and to a lesser degree, some researchers have experimented with ways of quantifying cultural information. However, due to the many factors influencing the way in which cancer patients perceive and respond to their illness, the qualitative approach is precluded from providing a complete and accurate account of how those patients truly perceive their illness as it provides only a narrow explanation, or a two or three variables relationship. In contrast, the qualitative approach enables the investigator to comprehend the exact meaning of the disease as expressed by the patients.

Mullen and Reynolds (1978) also suggested that quantitative studies generally have been static. They take a "snapshot" to describe conditions or situations at one or several points in time instead of moving pictures of processes as they vary under different conditions and interact with other variables, and the domains of time and space have not been taken into account. As well, relevant concepts often have been oversimplified when they were operationalized for quantitative measurement (Haase and Myers, 1988).

Using quantitative approach methods that incorporate questionnaires have also been found to be inadequate, as highlighted by Burgess in her study on "stress and cancer", in which she states "questionnaires which patients complete themselves have been criticized on the grounds that they ignore the meaning and context of stressful events, and because their scoring systems imply additivity" (Burgess, 1987, p.403).
Historically however, scientific advances have come from a combination of inquiry into the nature of the event and generalizations about that event as it exists in the world. For example, Freidian Theory, one of the most significant theoretical formulations and socially influential scientific advances in the twentieth century, was not derived from "how many" but by close observation and conceptualization about the nature of events. Therefore, qualitative research is a scientific method which provides a way to construct meaning that is more reflective of the world of practice (Swanson and Chenitz, 1982).

Qualitative research, which emphasizes understanding rather than explanation, relationship rather than causality, and processes rather than outcomes, has an important role to play in medical research. A qualitative approach in medical settings provides knowledge about two socio-cultural systems, client community; and the health care system. It is as participant observer, working within the health care system, that a researcher learns the health care structure, modes of operation, professional roles, and the goals of the organization and its individual members (Burkett and Godkin, 1983).

From the above discussions, it can be seen that a qualitative approach was useful to health professionals including the nurse researcher who wants to discover and enhance his or her understanding of the life experiences of cancer patients and explain how those patients adapt, both culturally and socially to their cancer illness and the changing conditions, that now exist for them. It is seen therefore, that the key to qualitative research is understanding the context in which those changes in life events occur (Leiningger, 1985).

As well, on reviewing the presented literature, it was clear that cancer patients' perceptions of their experiences were complex and difficult to predict as the meanings that they create depended on interpersonal, intrapersonal and environmental factors. Therefore, a qualitative research approach which emphasizes human behaviour and interaction was an appropriate means by which to understand cancer patients in their own surroundings.

Using a qualitative approach is viewed as an appropriate method to study the everyday, routine social interaction which occurs in a medical setting. Kleinman et al., (1978) recommended the application of qualitative studies as it not only enabled practitioners to step out of an ethnocentric professional framework, and recognize clinical reality as
being culturally constructed and pluralistic, but also, to recognize three structural domains of health care in society. These domains include, professional; popular (family, social network, community); and folk (non professional healers), with each domain having its own explanatory system of health and illness.

The results of Kleinman's study (1978) of patient and professional interpretations of diseases and management, indicated that patients and professionals behaved under different rules, values and structures, even though they were in the same culture or society. Clinicians searched for technological "fixes" to control disease problems, whereas patients (who also often searched for technological fixes) seek solutions to illness problems that were more given to psychological than to technological interventions. Patients tend to evaluate treatment success as "healing" of illness, for example, the provision of personal and social meaning and the management of life problems, rather than the "curing" of disease.

In any encounter between practitioner and client, cultural differences may occur as each have different understandings and expectations. As well, misunderstanding between practitioners and client often merge as the terminology used and understood by practitioners may differ from the terminology that is understood by clients. Furthermore, even though clients may use the same vocabulary as practitioners, this does not always imply that they share similar interpretations of events.

As nurses working in that area between the understanding of the practitioner and that of the patient, they must learn to identify with and understand the interpretations coming from both worlds. Leininger saw that a qualitative approach had been most valuable and important in identifying those worlds (Leininger, 1988).

**Illness, Disease, Medicine and Nursing**

A common saying implies that nursing is about 'caring' whilst medicine is about 'curing'. The central concern of medicine is to diagnose and treat diseases and pathologies, whereas for nurses, their role is seen as being concerned with actual and potential needs which emerge in response to illness or health problems (Dougherty, 1985). When doctors and patients attempt to give meaning to the sickness episode, there is a clear distinction between what the doctor interprets as being disease and what the patient perceives as an illness. That is, illness was defined as the way patients learned to perceive, interpret, communicate and cope with symptoms. Disease on the other hand, was defined as the way practitioners leaned to rearrange the patients' illness
experience within the theoretical models, taxonomy, and clinical expectations of their therapeutic system (Kleinman, 1980). This area of distinction was defined as being a crucial domain for nursing, wherein nursing dealt with treatment, assisting patients with discomforts and in adapting lifestyles to the illness or treatment. Gunter saw that:

Nursing care is the provision of personal care in a relationship of being "with" the patient as he experiences illness. It also includes assistance to the patient and to the physician with delegated aspects of the therapeutic regime (Gunter, 1986, p.5).

From this evidence, the nursing role was difficult to define, whereby the nature of nursing, in being concerned with the individual through interpersonal relationships in the area of health and disease, armed with a body of knowledge stemming from a theory of medical practice, causes problems of identity and meaning within nursing.

Basic Considerations in Nursing

Although many scholars have attempted to describe nursing, there is now general agreement among the leading writers in identifying four critical elements which are interrelated to form nursing's multi disciplinary matrix. These elements include human nature, environment, health, and nursing (Flaskerud and Halloran, 1980; Meleis, 1985; Fawcett, 1989; Moody, 1990a; and Chinn and Kramer, 1991). The way these metaparadigmatic domains are conceptualized and interrelated frames the different theories of nursing, the structure of which are open to evolution and change.

HUMAN NATURE

In nursing theory, the nature of humankind was described in terms of individual attributes, wholeness and integrity. Travelbee (1966) defined the human being as a unique, irreplaceable individual (a one time being in this world) unlike anyone who had lived or will live and where the illness experience of a single human being, family, or community has unique meaning. Henderson (1966) viewed patients as individuals who require assistance to achieve health and independence or peaceful death. As well, where the patient and his or her family were viewed as a unit, Henderson also saw the mind and body as being inseparable. Levine (1967) defined the person as a holistic being in interaction with his or her environment, a unity who is to remain conserved and integral. Rogers (1970) viewed the person as an energy field co-extending with the
universe where humans are perceived in their wholeness, interacting within a field of
dynamic forces. King (1971) saw individuals as reacting, time oriented, social beings,
with the ability to perceive, think, feel, choose, set goals, and make decisions. Orem
(1985) defined the individual as an integrated whole composed of an internal physical,
psychologic, and social nature with varying degrees of self-care ability. Newman
(1979) saw the client as part of a greater whole and multiple system levels in space.

ENVIRONMENT

Within the discipline of nursing, environment was consistently viewed as a central
concept (Chinn and Kramer, 1991). Several nursing scholars used this concept to refer
to all the influences affecting the behaviour and development of people. However, in
later models of nursing there was a shift in the interpretation of environment as society,
or culture. This shift was away from Nightingale’s early model, where the central focus
was explicitly on environment in which she believed that disease was a reparative
process and by altering the physical environment and placing the human body in the
best possible condition, would contribute to the reparative process and the patient’s
well-being.

In the development of these later nursing models, there was less attention paid to
environment per se and was generally viewed as encompassing the notion of society,
for example, Levine (1966) viewed society as the total environment of the individual,
including the family and nurse. However, environment became an important concept in
Leininger’s model, in that it influenced health and care patterns of individuals, families
and cultural groups. Furthermore, Leininger maintained that any study of individuals,
families and cultural groups, without reference to the environment or cultural context,
limits a full and accurate understanding of human beings (Leininger, 1985).

HEALTH

The concept of health in nursing has usually been conceptualized as, a dichotomous
variable (present or absent); a continuum (from wellness to death); or as an inclusive
holistic state. For example, Neuman (1982) defined health as being a condition where
all parts or subparts are in harmony with the whole of man. If man’s total needs are met
he is in the state of optimum wellness. Henderson (1966) believed that health was basic
to all human functioning where health and independence were interrelated, just as
illness was equated with dependence. As well, completeness and wholeness of mind
and body were viewed as a rarely achieved state of health. Roy (1980) viewed health
and illness as one inevitable dimension of the person's total life experience. When man's mechanisms for coping become ineffective, illness results. Alternatively, health ensues when man continually adapts to any given situation. Paterson and Zderad (1988) described health as more than just the absence of disease, in that individuals not only have the potential to reach a steady state of health or well-being, but also for more-being, where more-being implies the individual may join the process of becoming all that is humanly possible.

Other scholars recognized that health was perceived differently by the client and health professional as well as arguing that the physiological definition of disease was inadequate for the discipline of nursing. A concept, based on there being a distinction between illness and disease and which is described in medical anthropology, is used to reconcile those perspectives into the broader construct of health which identifies areas of professional and client congruence and incongruence (Tripp-Reimer, 1984).

NURSING

Nursing as a profession has been practiced for more than a century, but it is only in the past three decades that nursing theory has seen any substantial development. This development came about when nurse-scholars began to debate the question "What is nursing?" These debates brought forth the theoretical statements known as nursing conceptual models (Whall, 1989).

In most nursing conceptual models, nurse-scholars accepted that person was the focus of nursing (Whall, 1989) and that nursing action taken in response to a person's need as a visible expression of the art of nursing (Wiedenbach, 1964). Nursing was viewed as a helping profession that provides a service to individuals, as Abdellah defined:

Nursing is a service to individuals and to families; therefore, to society. It is based upon art and science which mold the attitudes, intellectual competencies, and teaching skills of the individual nurse into the desire and ability to help people, sick or well, cope with their health needs, and may be carried out under general or specific medical direction (Abdellah, 1960, p. 24).

Abdellah not only saw that nursing should provide a service to individuals, but also recognized the need to expand the scope of nursing beyond that of periods of hospitalization and to provide for the health care needs of the well person with concern
for preventative and curative measures. Although this was a step toward defining the subject matter of nursing, the insistence that these functions remain under medical direction, was to quickly become a point of contention among nursing scholars (Buckenham and McGrath, 1983).

Henderson, in proposing a separate and unique function for the nurse in the provision of basic nursing care, has been credited as providing the definitive statement on what that function should be. Henderson's statement, which has been widely accepted within nursing circles suggests that:

The unique function of the nurse is to assist the individual, sick or well in the performance of those activities contributing to health or its recovery (or to peaceful death) that he could perform unaided if he had the necessary strength, will or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible. (Henderson, 1966, p.15)

There have been many other concepts on the nature of nursing with the prime focus on interpersonal interactions. Peplau (1988) saw nursing as an interpersonal and therapeutic process where nurses were part of a team of health professionals all working in concert to help move the patient forward to creative and productive living. Peplau may have also influenced the work of Orlando with similarities appearing in nursing definitions that both focus on the interpersonal relationship between the nurse and patient (Meleis, 1985). Orlando (1961) described nursing as a process of interaction with an ill individual to meet an intermediate need. She identified that any nursing situation consisted of, patient behaviour; nurse reaction; and nurse action.

Travelbee (1966) put forward similar ideas as presented in other nursing models, in that nursing was an interpersonal process, whereby the professional nurse practitioner assists an individual, family, or community to prevent or cope with experiences of illness and suffering and, if necessary, to find meaning in those experiences.

King (1971) viewed that nursing was an interpersonal process of action, reaction, interaction and transaction, whereby patient and nurse meet, understand each other and thus, the patient in need of help was offered the appropriate nursing assistance, whereas Wiedenbach (1964) was concerned with providing for patients' needs through meaningful and clear actions and that nursing, as "a helping art" was designed to assist when the individual became in need of help.
In the literature reviewed in this section, the nature of nursing was seen as being involved with holistic beings whose needs were met through meaningful interaction. Although there are important differences in definitions and conceptualizations, the ideas presented by various authors on the nature of nursing, consistently put interpersonal interaction at the prime focus. Some authors were concerned with nursing direction and actions taken in achieving interaction with the direction being defined by the care recipient. The nursing role was then seen as facilitator and when incorporated into a theory or model, nursing was seen as enabling the will and behaviour of the recipient. Others viewed the interpersonal process as being shared or initiated by nurses where nursing processes and actions rests on the nurse's initiative, knowledge and approaches. Theoretical ideas place emphasis on nursing actions as the key to achieving goals or purposes of interaction. Whether interaction is achieved through client direction, or nurse initiation, the significant point to be made here is the recognition that human interaction creates human health and wholeness (Chinn and Kramer, 1991).

It must be noted that within the four basic concepts which were found in each nursing model, there has been a shift in the area of emphasis. In Nightingale's model, the emphasis was on the environment; in the 1950s there was a shift in the concept of nursing; the 1960s saw person become the dominant focus; and in 1980s, the concept of health was the centrality of the nursing model. Currently, there appears to be a new emphasis emerging with focus on symbolic interaction of person and environment and which has assumed more importance in nursing practice and nursing research (Moody, 1990a).

As previously mentioned, certain nurse-scholars had embraced the concepts of person, environment, health, and nursing as constituting a metaparadigm of nursing. Leininger however, firmly held to the position that human care was the critical and essential element of nursing and was a central concept of a metaparadigm of the discipline. Leininger (1984) viewed care as essential to human health and well-being and the major feature distinguishing nursing from other disciplines.

Leininger, in recognizing cultural factors as being valuable for nursing practices, stated "We are entering a new phase of health emphasis as we examine the impact of cultural factors upon human caring, health and illness behaviours" (Leininger, 1978, p. 123).
Leininger (1984) emphasised the historical, cultural, and social context of human beings in order to explain and predict the broad dimensions of human care behaviours. The major objective of her theory was to improve and advance the quality of care of people through the deliberate and creative use of transcultural knowledge that reflected culturally congruent care based on the values, beliefs and life styles of people from different cultures. Culturally derived nursing care actions and interventions were predicted to maintain client health, improve client satisfaction and to help clients recover readily from illness or disabilities (Leininger, 1984). With the improvement of care for humankind at the focus of her belief, nursing was defined as "a learned humanistic art and science that focuses upon personalized (individual and group) care behaviours, functions and processes directed toward promoting and maintaining health behaviours of recovery from illness" (Leininger, 1984, pp. 4-5).

The theory of cultural care diversity and universality to influence and guide nursing practice as seen by Leininger, has yet to be realized. However, with the increase in cultural identity bringing an increased demand for culturally sensitive and specific care and practices to assist patients of diverse cultures, this theory holds great potential for enhancing quality humanistic and holistic care of all cultures (Luna and Cameron, 1989).

**Nursing Practice**

For many years the base knowledge of nursing practice came from the traditional 'hands on' approach where principles and rules were memorised and passed along during 'on the job' training methods or through the rather limited apprenticeship forms of education. With no further education available for the nurse novice, most of what would be termed as nursing knowledge was gained through many years of experience. Nursing practice's early principles were sometimes derived from scientific knowledge or the generalizations of other disciplines whilst others came from generally accepted facts, the unquestioned traditions of practice, and techniques that were thought to be sound. All these approaches were molded together to what became the basis of nursing practice.

Although change came slowly for the development of nursing knowledge, nursing philosophy and ideology, the idea that nursing required a distinct body of knowledge for practice remained entrenched in the ideals of early nurse-scholars (Abdellah, 1969; Hall, 1964; Henderson, 1966; Orlando, 1961). This commitment to a distinct and
A separate body of knowledge grew from the realization that, although the aims of nursing and medicine were similar and related, the prime goals and functions of nursing required knowledge that was not drawn from medicine or for that matter, any other single discipline outside of nursing (Chinn and Kramer 1991).

However, attempts to reform nursing as an intellectual discipline in its own right, have taken two general directions. One direction tends to follow models of other professional schools, especially that of medicine and which stresses the development of nursing as a profession and to treat nursing as an applied science. The second tendency was to seek help from other natural sciences by copying their theories and research procedures in the study of nursing. These applied science approaches to nursing come from an army of theorists who tend to be equally prolific in the production of theories which more than likely do not spring from actual practice. The resulting application of these theories to nursing practice brings about a loss in nursing's sense of unity and integrity (Bishop and Scudder, 1990). As well, it has been the cause of much frustration to nursing clinicians in attempting to implement these nursing theories in practice settings (Parker, 1988).

Donaldson and Crowley (1978) in pointing out that nursing, rather than developing as an applied version of some other academic discipline, suggested that nursing's developed body of knowledge whose development paralleled other academic and professional disciplines, should be considered as a science in its own right. The idea of treating nursing as an applied science was inappropriate, as Bishop and Scudder explained:

For practices such as nursing to progress, they must be studied in ways appropriate to the practice itself. Thus, the sense of nursing should be articulated by the human sciences because nursing practice is a human achievement which fosters human well-being through a special caring relationship between nurse and patient. Therefore, although nursing uses natural and social science, nursing itself cannot be adequately understood as applied science. Applied science degenerated practice into mere technique, whereas the human sciences articulate nursing as practiced. In so doing, they avoid the separation of theory and practice which results from applying theories drawn from outside nursing to nursing practice. (Bishop and Scudder, 1990, p.174)

The need for nursing to develop its own theory from an empirical base rather than relying on other disciplines has become the focus for many nurse-scholars (Quint, 1967). It should be pointed out however, that although nursing has borrowed from
other disciplines, nursing has already developed theories that were applied uniquely to the perceived concerns of nursing practice (Bishop, 1989).

The main thrust of this argument is not to dwell on whether what at present makes up nursing theory has been borrowed, solicited, adapted or derived from other theories or rooted in other disciplines, but rather, as Ellis points out "Theory, whether begged, borrowed, derived, or originated by nurses, is significant for nursing if it can enlighten nursing practice" (Ellis, 1968, p.222).

There have been many calls to strengthen the autonomy of nursing discipline by developing a single, unifying theory which nurse-scholars hoped would provide a positive direction for nursing to follow. At the present time however, it is widely accepted that the value of theoretical pluralism has helped to answer certain questions in nursing (Fitzpatrick and Whall, 1989) as well as being essential for studying nursing in which the core of the discipline is concerned with addressing the multiple realities in the complex human phenomena (Moody, 1990a).

**Being In-Between**

The relationship which exists between doctor, nurse and patient begins with an illness (Kestenbaum, 1982) which brings the patient to the doctor. Generally, the doctor patient relationship is initiated by the illness experienced by the patient rather than by the disease diagnosed by the doctor. The real hospital situation comes into being when the nurse is invited to guide the patients through the alien world in which they find themselves and where the nurse serves as an intermediary between the doctor and the patient by interpreting the doctor and his activities to the patient. At the end of the day, and regardless of where the nurse is seen to ‘fit in’, the responsibility of providing holistic patient care, rests with them.

Engelhardt noted that the situation in which nurses found themselves as mediator and who "give their care under the scrutiny of two rather powerful individuals, the patient and the physician" (Engelhardt, 1985, p.71), tended to be one where the nurse was caught in-between the patient's rights and the doctor's authority. The power vested in doctors stemmed from his acquired expertise and technical skill in medicine and health care matters. As well, the legal right to perform essential surgical procedures and to prescribe drugs, lent weight to that authority. The legal rights extended to patients in deciding the extent of what care was provided also made them a source of authority.
In being caught between doctors and patients the nurses’ rights and authority tended to be rather ambiguous and led to a feeling of powerlessness. However, as found in the studies of Samuelson (1991), the position of nurse as intermediary was not in itself ambiguous, but rather, one where nurses were faced with a dilemma when trying to put their view into practice. Being close to patients, nurses find themselves as communicators of illness information but are still subjected to the doctors’ monopoly of knowledge and to the decisions of the doctor in relation to treatment procedures. The patient recognizes the nurse as a representative of the professional medical establishment, although that establishment ranks nursing below that of the doctor and are accorded a position similar to that of patient. Nurses however, with no independent task in relation to nursing care as well as carrying out the hospital’s daily routine and obeying the doctor’s orders, rightfully feel that they are an assistant rather than a true representative of medical science.

In contrast, the in-between element of nursing practice, was viewed by some interpreters as a privileged unique position, whilst others, in their obsession to develop their autonomy, obscured or clouded the issue on the in-between element of nursing (Bishop and Scudder, 1990). Being in-between also meant that nurses were often in a position where they could promote optimum patient care. As well, their position made it possible for them to be an effective patient advocate. Gadow (1980) contended that the nature of nursing practice placed the nurse in the role of existential advocate for the patient as well as emphasizing the need for nurses to help patients understand the meaning of their experience of illness. In summarizing, Gadow saw "advocacy nursing as the participation with the patient in determining the personal meaning which the experience of illness, suffering, or dying is to have for that individual" (Gadow, 1980, p.97).

Bishop and Scudder (1990) argued that although it was difficult for the nurse to make decisions without taking into account the roles, rights and possible responses of doctors, patients and hospital administration, the in-between situation in which she was enmeshed, set the context in which those decisions were made and did not remove her decision making responsibilities. Bishop and Scudder (1990), in pointing out that the well-being of the patient is the prime concern of nurses who remain true to their calling and follow the moral sense of their vocation, compared the health care profession with other business oriented vocations where work ethics were not controlled by a moral sense, and where those involved may find themselves in a situation between profit and conscience. They also suggested that situations of this nature should not develop for
nurses in making moral decisions along with other workplace professionals if all keep the well-being of the patient as the prime focus of their concern. Nurses, as direct caregivers were seen as being in a unique position for making moral decisions by the very fact that they decided from a position of in-between.

The cry for the right of nurses to make moral decisions, came at a time when nurses were reacting to the dominance of doctors and their increasing reliance on scientific and technological 'fixes', by emphasizing aspects of a holistic approach to nursing that is to do with humanism and the dignity of the patients. As well, it was a way of forming an independent nursing identity which places stress on a holistic view and where the knowledge of the patients' illness and experiences were central.

**Nurse and Patient's Experience of Illness**

Concern over providing holistic care to patients that includes professional attention to aspects of illness experiences of the patients, is growing among nurses and other health practitioners. In this holistic-care view, people become patients when the severity of their illness is enough to lead them to seek medical help. Both illness and becoming a patient are human experiences, and whilst the experiences of pain and suffering are intensely felt, the focus of the patient is on illness and how it affects their life ways. The nurse, on the other hand, is focused on the patient, the distress and symptoms, and how she can be of help to the patient.

Therefore, nurses need to understand patients' experiences of illness as they are the ones who work with the patient and help them live through their illness episodes (Travelbee, 1966). As well, nurses act like agents who speak for patients. Samuelson made this point in writing "As nurses speak for patients . . . expressing solidarity with those who cannot explain themselves in the relevant 'language' (Samuelson, 1991, p. 201)."

In the provision of help, where one professes to truly speak for the patients, an understanding of illness experiences from the patients' point of view is essential. The essence of this understanding is that nurses try to enter the patient's world and to see the illness through the patient's eyes.
Understanding Patient's Experiences of Illness

In order to understand complex human responses to illness that are commonly investigated in nursing research, qualitative research methodology focusing on ethnography is necessary (Leininger, 1987). This is because ethnographic research is a highly systematic research approach for the collection and analysis of qualitative data for the purpose of rendering a true to life picture of what people say and how they act, whilst people's words and actions are left to speak for themselves (Taylor and Bogdan, 1984). In the field of anthropology this approach is viewed as being suitable for developing concepts toward an understanding of human behaviour from the people's point of view.

It is true, that in a complex illness like cancer, investigation must extend into the socio-cultural sphere where the illness holds a specific and dissimilar meaning for all cultures as well as for every individual within the cultural group (Nielsen, 1989). An ethnographic approach which places emphasis on the concept of culture as being basic to human care (Leininger, 1984; Hogan and DeSantis, 1991) is seen as being the most appropriate method to study the experience of cancer patients.

Within Thai society as in other societies where doctors generally do not tell patients the true diagnosis, any attempt to understand the meaning and experience of cancer as it is defined by Thai cancer patients becomes rather difficult as the researcher cannot go and ask the patients directly what they think about having cancer. Therefore, if the ways by which direct questioning of patients about cancer were limited because of concerns in invoking a distressful situation for them, then the question, How does one get the information directly from them?, remained to be answered.

The question of how to study Thai cancer patients was seemingly more complicated than first envisaged as much of the data of past studies have been ascertained by a dialogue between researcher and the patients in which the meaning of words and actions were always being interpreted and reinterpreted. However, this question was finally resolved with the selection of an ethnographic research method which depended principally on field work and where the researcher places herself self into the community life of the cancer patients. And so, as originally envisaged, by living with, talking to, and observing the patients who were at the centre of this study, data was provided for a detailed description of the experiences of Thai Cancer patients.
This research was based upon the ethnographic anthropological traditional inquiry. In such research methodology, the researcher enters the study, not with a specific experimental hypothesis, nor with a fettered conception of the research setting, but rather with a particular theoretical focus. This present research focused on Thai patients' experiences of their cancer illness and treatment and on their relationship with the professional medical system, their families, friends and acquaintances during the course of the sickness.

Finally, the research method provided this researcher with an opportunity to look beyond reports of behaviour and to observe the behaviour herself and therefore assess the correspondence or the discrepancy that existed between the real and the ideal cultural statements. As well, the prolonged residence in the studied community and the on-going relationships provided greater opportunity to check the reliability of informants.
CHAPTER 3

METHODOLOGY

Introduction

In previous chapters it has been concluded that an ethnographic approach would be called for in order to understand the aspect of lived-experiences of the Thai cancer patients. This need to learn and understand the life situations of those patients was the main reason for encountering and describing their experiences first hand, endeavouring to make some sense out of it. Therefore, this study, like other research studies that "emphasizes encountering alien worlds [in this case, the patients world] and making sense of them is called ethnography" (Agar, 1986, p.12).

Unlike other qualitative approaches, including phenomenology from the existentialists (Heidegger, 1962), and grounded theory (Glascr and Strauss, 1967), ethnography is grounded in the cultural concept to capture and understand the peoples' way of life within specific environmental and cultural contexts. Thus, ethnography in the broader sense, as defined by Leininger, is "the systematic process of observing, detailing, describing, documenting, and analyzing the lifeways or particular patterns of a culture (or subculture) in order to grasp the lifeways or patterns of the people in their familiar environment" (Leininger,1985, p.35).

In this chapter, the theoretical orientation underpins an ethnographic approach, which has long been the domain of the anthropologist, will be discussed, whilst traditional or humanistic ethnography which underlines this study, will also be put forward for discussion. More specifically, the methodology which is borrowed from cultural anthropology and which contributes to this chapter is concerned with the explanation of ethnographic research methodology and its appropriateness as an approach to the empirical problems discussed in previous chapters.
Theoretical Orientation

There are many theories that ethnographers have proposed or applied to their study. These theories however, all share a common concern of investigating the ways in which human actors themselves construct the social world through their interpretation of and interaction with human actors that is shared in symbolic interactionism.

In general, symbolic interaction is a theory of human behaviour that focuses on the meaning of events to people in their natural setting (Blumer, 1969). Symbolic interaction is related to the school of philosophy known as phenomenology, which takes the view that reality is constructed through human action and does not exist independently of it.

Phenomenology as expounded by Edmund Husserl (cited in Gorman, 1977) relates to methodology in terms of subject-oriented epistemology. Within this philosophy, Husserl claims that consciousness is the substructure or root of all knowledge (Schutz, 1972). As such, human experience can be understood in terms of the structuring activity of consciousness and the interdependence between the perceiver and the object perceived (Toombs, 1987). According to Husserl, in order to understand the structure of existence one must first suspend the 'natural attitude' of taken-for-granted beliefs and set aside personal concepts of reality, thus leaving the way clear to fully enter into an individual's world, a process which he referred to as phenomenological "reduction" or "bracketing" (Toombs, 1987). This idea has led to criticism, in that there is the risk of being branded with having the view that the self is the only source of knowledge (Kultgen, 1975).

Following Husserl's writings, Alfred Schutz developed the idea of phenomenological philosophy into more sociologically grounded concepts. Schutz (cited in Gorman, 1977) agreed with Husserl that one's beliefs are scientifically justifiable through self-conscious awareness which is the ultimate foundation of knowledge. However, he departed from Husserl's view by attempting to find a phenomenological foundation by observing human action in a society in which individuals are consciously aware of sharing the same world (Schutz, 1972). Thus, in the social world, people must observe and interpret one another in order to interact in and understand that world. In other words, people come to understand one another through intersubjectivity. On this, Schutz wrote:
We considered the general understanding we have of the other persons subjective experiences, and we found that this understanding is based on our own subjective experiences of him. Once the existence of the Thou is assumed, we have already entered the realm of intersubjectivity. The world is now experienced by the individual as shared by his fellow creatures, in short, as a social world. (Schutz, 1972, p.139)

In phenomenological philosophy, action and meaning are the central concerns. Within these concerns, empirical works have been developed with symbolic interactionism being one of the most successful (Robin, 1976). Both phenomenology and symbolic interactionism are concerned with the study of the intentions of human behaviour, that is, how people define their world and how they act in relation to their beliefs. According to symbolic interactionism theory, meanings are created through the interaction between humans and their social surroundings (Blumer, 1969). The originator of symbolic interaction was Mead (1934), whose main interest centred around mind, self, and understanding human nature through interaction of social processes.

Blumer (1969), further expands on Mead's work, stating that symbolic interactionism rests on three basic premises. The first being, that "human beings act toward things on the basis of the meaning that the things have for them" (Blumer, 1969, p.2). These things may be other human beings, objects, institutions, ideals, or a combination of these which are present in the individual's world. Secondly, the "meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows" (Blumer, 1969, p.2). Thus humans learn how to see their world by interacting with other people. Thirdly, "these meanings are handled in, and modified through, an interpretive process used by the person in dealing with things he encounters" (Blumer, 1969, p.2). Therefore, through a process of interpretation, humans apply meanings to situations, others and things as well as to themselves.

From these three basic premises, the definitive features of symbolic interaction are on the process of interaction between people and on the social organisations which have been developed. For social life, group action is essential, individuals form, interpret and evaluate their own and others actions and they create their own world through self-consciousness and within the interaction process, individuals are able to fit their respective lines of action to one another (Robin, 1976). The meaning of actions here are seen as social products, and are created by sharing the meanings with the people of that social group, "otherwise social life would not exist" (Ellen, 1984, p. 29). Meanings arise because within the interaction process, people share the same basic symbolic order of meanings, definitions and situations (Denzin, 1969).
A key element of symbolic interactionism is that in order to understand peoples' actions, the researcher must use an approach that gives access to the meanings that guide those actions (Hammersley and Atkinson, 1983), and that approach demands that the researcher adopt an attitude of respect toward the social world. On this, Blumer states:

My conclusion . . . can be expressed as a simple injunction: Respect the nature of the empirical world and organize a methodological stance to reflect that respect. This is what I think symbolic interactionism strives to do. (Blumer, 1969, p. 60)

Symbolic interactionist perspectives are concerned with the creation and change of symbolic order through social interaction. This has important implications for how symbolic interactionists view research. While positivists view methods as techniques of data-gathering for the testing of theories, the symbolic interactionists view research methods as a socially organised enterprise based on interactions (Silverman, 1985).

Denzin, (1969, 1971, 1978) made several attempts to formulate what he saw as the basic methodological stance of symbolic interactionism, and pointed out that “Methodology represents the principal ways the sociologist acts on his environment” (Denzin, 1978, p.6) whilst also arguing that the researcher must be fully aware of the interactional features of his own conduct. He does this by being familiar with the personal interpretations which he attaches to those social events encountered and the inherent demands of those encounters, inclusive of interviewing and observing other actions and the emergent character of interaction that effects the type of data he will produce. As can be seen from the literature thus far reviewed, all social research is founded on the human capacity for participant observation.

Following the common practice of symbolic interactionists, Denzin (1978) suggests that participant observation is the most appropriate research methodology. This method allows the researcher to actively enter the subject’s world and interpret that world through the understanding of the behaviours, languages, definitions, attitudes and feelings of those who participate in it (Denzin, 1971). Unlike survey research, Denzin (1978) points out that the participant observer is not bound in his fieldwork by pre-judgements about the nature of his problems, by rigid data-gathering devices, or by hypothesis.
However, in conducting participant observation, the researcher may encounter a number of difficulties that could more than test his resolve in his efforts to become part of the scene (Denzin, 1978). The observer may 'go native' or 'over-identify' with the participants to a degree that he loses sight of his original intentions (Denzin, 1978). As well, by focussing on the present, the observer may become blinded to past important events. Hammersley and Atkinson (1983) point out that in this situation, not only may the task of analysis be abandoned in favour of the joys of participation, but even where it is retained, bias may arise from over-rapport. However, in the field of anthropology, Jules-Rosette (1978) and Van Maanen (1983) argue that the researcher can be constantly aware of their research and must learn to project themselves as the principal and most reliable instrument of observation selection, coordination, and interpretation.

**Ethnography as Methodology**

Originally, anthropologists referred to ethnography as the study of another culture and described the exotic ways in which that groups of people in that culture view themselves, their relationships to others, and the rest of the environment around them (Werner and Schoepfle, 1987).

The origin and development of ethnographic research methods are associated with anthropology and can be traced back to the works of Franz Boas in 1920 (1948), Bronislaw Malinowski in 1922 (1983) and Margaret Mead in 1929 (1931). These anthropologists used the field technique to discover what the world was like for those who live differently. This technique later developed to be a unique method in anthropology, requiring intensive fieldwork among a small population where the investigator had to live and participate over a long period of time in order to get "in-depth" and "holistic" information. In noting this steady development, Germain saw that for the ethnographer:

... one becomes part of the subculture being studied by physical association with the people in their setting during an extensive period of fieldwork. Through the essential methods of participant-observation and intensive interviewing of the members of the subculture, the researcher learns from informants the meaning they attach to activities, events, behaviours, knowledge, artifacts, rituals, and other aspects of their lifestyle. Participant-observation research aims at producing ethnography. (Germain, 1986, p.147)
And so, for about three quarters of a century, anthropologists had gone out to study peoples in various parts of the world, recording the legends, the beliefs, the daily life and the social relations that they found. They called these descriptions of the way of life of a people, ethnography (Alger, 1974), which is really the learning from people rather than just the study of people (Spradley, 1980).

Ethnography is regarded by such researchers as "An anthropologist's "picture" of the way of life of some interacting human group, or, viewed as process, ethnography is a science of cultural description" (Wolcott, 1975, p.112). Therefore, an ethnography is a product and a process of the study of living people in a particular culture or subcultural group. As a product, ethnography is a description and analysis of the way of life, or culture of society that identifies the behaviours, beliefs, understandings, attitudes, and values they imply, found in that social world. As a process, ethnography is the traditional research approach to the development of theories of culture by the anthropologist that deals with living people (Germain, 1986).

The present research employs a methodology based upon the ethnographic anthropological traditional inquiry, wherein the researcher enters the study, not with a specific experimental hypothesis to be tested, nor with a fettered conception of the research setting, but rather with a particular theoretical focus. The focus of this present study then, was on Thai patients' experiences of cancer illness and treatment as well as their relationship with the professional medical system, their families, friends and acquaintances during the course of their illness.

Ethnography as Method

Traditionally, and even today, ethnographic methods are still influenced by Malinowski (1983) where they are seen to depend principally on fieldwork, whereby the researcher places himself or herself into the communal life of the people who he or she wants to study. The importance of living in a chosen field and conducting personal observations has not changed for the ethnographer (Sanday, 1983). Ethnographers try to convey a sense of "being there" and experiencing settings first-hand, coming back with information about how people live there and making that information available to the professional community in a practical form. Being a study of the social world, it is as Van Maanen points out:
... at least partially ethnographic if it allows a researcher to become immersed in the everyday life of the observed. In essence, the use of such techniques in organizational studies literally forces the researcher to come to grips with the essential ethnographic question of what it is to be rather that to see the member of the organization. (Van Maanen, 1983, p.52)

In entering into the peoples' world, the researcher participates overtly or covertly in their daily lives for an extended period of time, watching what happens, listening to what is said, asking questions, in fact, collecting behavioural data. With ethnographic information, ethnographers try to render a descriptive, true to life picture of what people say and how they act, thus allowing the peoples' words and actions to speak for themselves (Taylor and Bogdan, 1984).

In ethnographic fieldwork, participant observation is supplemented by a variety of data collection techniques, which are employed depending on the problem, access to data and theoretical orientation. They may range from key-informant interviewing, collection of life histories, structured interviews, questionnaire administration, to the recent technique of ethnoscience. The main reason for employing a variety of data collection procedures is that it enables the investigator to cross-check results obtained from observations and those recorded in fieldnotes (Wolcott, 1975).

**Ethnographic Description**

Wolcott (1975), in viewing ethnography as "the science of cultural description." saw that an ethnographer aims to describe the activities of a group of people locating their activities within the various contexts in which they occur. However, for the ethnographer, the task to produce ethnographic description is not so simple, rather it is complex and problematic. An ethnographer, as Emerson points out:

... is not interested in the commonplace or extraordinary in and of themselves, but in the ways in which the commonplace and extraordinary - all of the actions and event comprising the life of the people - are oriented and responded to, comprehended and guided by, the interpretations of group member. The central focus of ethnographer is not the "things in themselves" - if indeed there are such things - but things as there are grasped and shaped through the meaning conferring response of members. For some, the fact that groups impose structures of meaning on "things" comprises the mandate of ethnography and indeed in social science. (Emerson, 1983, p. 22).
Therefore, ethnographic description is not just a description of events and activities in the lives of those studied in themselves, but rather, the ethnographer's representation of them. According to Geertz (1973), ethnography should provide a "thick description." Borrowing the concept from Ryle's notion, he illustrates thick description by referring to a wink. He concludes:

... the point is that between what Ryle calls the 'thin description' of what the rehearser (parodist, winker, twitcher ... ) is doing ("rapidly contracting his right eyelids") and the 'thick description' of what he is doing ("practising a burlesque of a friend taking a wink to deceive an innocent into thinking a conspiracy is in motion") lies the object of ethnography: a stratified hierarchy of meaningful structures in terms of which twitches, winks, fake-winks, parodies, rehearsals of parodies are produced, perceived, and interpreted, and without which they would not (not even the zero-form twitches, which as a cultural category, are as much non-winks as winks are non-twitches) in fact exist, no matter what anyone did or didn't do with his eyelids. (Geertz, 1973, p.7)

According to Geertz, description of the social world is not concerned with contractions of the eyelids, but with the interpreted significance of winks, twitches, parodies and so on. Frake also notes, that since culture is "what the natives think is what in fact constitutes as cultural doings and cultural objects the body movements, vocal noises, and material artifacts produced by humans. Culture, the object of our description, resides within the thinking of natives" (Frake, 1988, p. 61). In reviewing the two descriptive styles, Frake concludes that "No ethnographer with any sense would purposely ignore either what people do or what people say about what they do" (Frake, 1988, p. 66). Emerson points out that thick descriptions should:

... present in close detail the context and meaning of events and scenes that are relevant to those involved in them. This task requires the ethnographer to identify and communicate the connections between actions and events, especially those salient to the variety of local actors themselves. In this sort of descriptive enterprise, actions are not stripped of locally relevant context and interconnectedness, but are tied together in textured and holistic accounts of social life. Ethnographic thick description proceeds on the assumption that context is not an obstacle to understand but a resource for it. (Emerson, 1988, p. 25)

Ethnographers are consequently confronted with a multiplicity of "complex conceptual structures" in which thick description places the many interpretations of events within their social contexts. As the most significant data is the sum of "our own constructions
of other people's constructions of what they and their compatriots are up to", analysis involves "sorting out the structures of signification" (Geertz, 1973, p.9). It is up to researchers then, to position themselves in order to view behaviour within the context of its setting, as well as gleaning from those at the centre of their observations "structures of meaning which inform and texture behaviour" (Wilcox, 1980, p.2). In this tradition, Conklin stated:

An ethnographer is an anthropologist who attempts . . . to record and describe the culturally significant behaviours of a particular society. Ideally, this description, ethnography, requires a long period of intimate study and residence in a small, well defined community, knowledge of observational techniques, including prolonged face-to-face contact with members of the local group, direct participation in some of that group's activities, and a greater emphasis on intensive work with informants than on the use of documentary or survey data. (Conklin, 1968, p.172)

Ethnographic Study of One's Own Culture

Traditionally, a large number of anthropologists devote their studies to the customs, the culture and the social life of living people. In order to carry out their cultural studies, most anthropologists of earlier days, such as Malinowski (Trobriand Islanders, 1922), Radcliffe-Brown (Andaman Islanders, 1922), Lowie (Crow, 1935) went out to various parts of the world and attempted to study the primitive people in every aspect of their native life. Some anthropologists however, turned their interests from the tribal people to other social units and found that their holistic descriptions were appropriate for the study of those units as it had been for the tribal people in those earlier times.

In present times, the cultural knowledge of living people can be studied by specializing in any one part of their social life such as religious ceremonies, illness, healing, economic systems and so forth. With the analysis of the events at the focus of their studies and how they related to the culture as a whole, anthropologists hoped that it would give a view of the overall cultural picture (Alger, 1974).

Not all anthropologists are interested in the cultures of other societies and it has been seen that an increasing number are now concerned with the customs and behavioural patterns within their own society. The trend toward applying the ethnographic study to any social unit of one's own society represents one of the main characteristics of
applied anthropology. For example, the nurse researcher applied ethnography to a
cancer unit (Germain, 1979), and the education researcher applied that same method to
the school (Wolcott, 1973). However, through the studies of one's own society, an
ethnographer has indeed found that it is very different from studying another culture
and also has profound theoretical and even epistemological implications (Ohnuki-
Tierney, 1984).

With these fieldwork considerations in mind, the ethnographer becomes part of the
situation being studied in order to feel what it like for the people in that situation. The
ideal fieldworker lives in the exotic setting, adapts to the host culture by overcoming
the culture shock, and thoroughly enjoys the experience regardless of any personal
discomfort felt as a stranger (Frake, 1988). The role of stranger or the outsider is
claimed as having a privileged situation to promote both perception and curiosity which
is essential to research (Aguilar, 1981). The insider researcher, on the other hand,
cannot claim the role of privileged stranger (Aamodt, 1981) and faces the problem of
becoming too familiar or too close to the culture being studied. This attachment to
one's own culture can mean that important pieces of data are overlooked as well as
inhibiting the perception of the structures and patterns of social and cultural life

Ohnuki-Tierney (1984), in recognizing that the current trend in anthropological
fieldwork is toward studying one's own culture, suggests that before one attempts any
such undertaking, it is of paramount importance to firstly distance oneself from their
own culture. This " distancing" is accomplished, according to Ohnuki-Tierney, by
going out and studying another culture. This idea has been supported by many
anthropologists on the assumption that one comes to understand something by seeing it
as an outsider and as a researcher, having had experience in studying another culture, is
likely to perceive more acutely the 'shades of difference' observed within one's own
culture, differences that otherwise may be ignored (Sanday, 1983).

Wolcott (1975), after citing the many arguments for anthropology being a cross-cultural
discipline and for the ethnographer to possess certain "essential ingredients" among
their credentials, does however, go on to argue that prior experience in the study of
other cultures is not an absolute necessity in doing ethnography, especially if most of
the other attributes the ethnographer is accredited with, are present. The attributes that
Wolcott saw as being compensatory factors included, "writing skills, essential for
validation; sensitivity as an observer; extensive reading on studies of other societies;
along with other less tangible faculties."
Another important issue that directly concerns the insider researcher, is that they are criticized as being inherently biased in their research programmes, in that they have leanings toward the betterment and the promotion of the interests of those being studied and tend to select and interpret what they see and hear in ways that are favourable to their own pre-selected goals, rather than presenting a disinterested search for the truth (Aguilar, 1981).

In contrast, the outsider in being free of "commitments to the group, can more readily acquire the strategic role of relatively objective inquirer "(Simmel, quoted in Merton, 1972, p.32). That is, by non-involvement with the study group, it is more likely that the outsider "surveys conditions with less prejudice; his criteria for them are more general and more objective ideals; he is not tied down in his action by habit, piety, and precedent" (Simmel, quoted in Merton, 1972, pp.32-33).

There are some studies that show evidence of bias in relation to selection of data and formulation of conclusions. However, Aguilar (1981) claims that examples are few with little that could be labelled as dishonest. In further pointing out that the risk of such bias occurs in all research, he mentions:

Bias is the human condition, a danger for both insider and outsider researchers. Whereas the insider might labour under a biasing chauvinism, all outsiders, by virtue of their primary socialization in one society, must make effort to overcome ethnocentric bias. Similarly, the xenophilia of some socially mobile or ethnically passing individuals is also a possibility for the exoticist (outsider) who see much virtue abroad and little at home. (Aguilar, 1981, p.22)

There are several advantages enjoyed by ethnic insider researchers in studying one's own culture, with possibly the most often claimed being that they have a definite head start in being part of the society from the beginning, and because "they shared frames of reference and consensual meanings, interaction is more natural and they attain a more thorough rapport with informants" (Aguilar, 1981, p.18). It is seen then, that this capability of the insider researcher allows them to engage in participant observational research to a far greater extent than can be achieved by the outsider.

However, both insider research and outsider research have inherent advantages and disadvantages, and they can indeed both play important roles in helping us understand not only the lives of others but our own lives as well. As Wolcott, who had experience in both research approaches, mentioned:
While I have gained essential and invaluable insight into cultural process in fieldwork there [refers to his research conduct in exotic settings], I have also come to appreciate how much more fully I am able to observe and to understand what goes on in the society (or more precisely, in those microcultural systems) in which I am a genuine rather than a would-be participant. Only here [refers to his research conduct in the American public school], I feel, do I observe, participate, and write under conditions in which I am most likely to understand most of what going on, with humour, nuance, double entendre, conflicting explanations and so forth all apt to go unnoticed rather than unnoticed. (Wolcott, 1981, p. 265)

Aguilar (1981) and Aamodt (1981) make the point that ethnic insiders, in doing research in one's own culture, are generally not so far immersed inside those cultural settings as outsiders would have us believe and because the many sub-groups forming society are separated geographically into culturally different and isolated groups, researchers are not likely to be identified as complete natives within that group.

Where a situation exists in one's own sphere of interest that requires an investigative study, it is preferable that the study is carried out in a setting that is different, but can provide conditions that are similar to that in question, thus dispelling any thought of the researcher being familiar with the chosen setting (Field, 1989). Therefore, when one enters a new setting it is desirable to do so as a stranger which shows a realization on the researchers part that one is neither comfortable with nor fully knows of those to be studied.

**Ethnographic Study of Health and Illness**

Ethnography as it is today, is not the sole domain of the anthropologist with study approach privileges for that select group alone, but rather, it has become increasingly popular among other social scientists. The view held by those social scientists on the pliability of ethnographic study, is that "one can take an ethnographic approach to studying virtually any aspect of human social life" (Wolcott, 1975, p.112). Accordingly, educational researchers were to conduct ethnographic studies of teachers and children in the school (Hargreaves, Hesterr and Mellor, 1975), whilst sociologist practiced this approach in the industrial work place (Pollert, 1981), and nursing researchers explored patients' conceptions of their sickness in the ward or hospital setting (Germain, 1975, Aamodt, 1972). From these examples, it can be seen that just about every social science discipline has practiced an ethnographic approach in their studies.
It should perhaps be noted, that ethnographic approaches to the understanding of illness are not new. As has been seen over the last two decades, there have been many studies conducted using this approach with most coming from work in the field of anthropology (Turner, 1967; Fabrega, 1974; Kleinman, 1980; Eisenberg and Kleinman, 1981; Ohnuki-Tierney, 1981). All of these studies have attempted to elucidate the rationale underlying the individual's interpretation of the nature of their illness.

Recent ethnographic studies (Good, 1977; Blumhagen, 1980; Lang, 1989) have provided detailed descriptive data based on the patients' point of view. All of these studies stress the importance of patients' statements concerning their illness with data from these studies being obtained by researchers through direct discussion with their patients. This kind of information is critical in enabling health care workers to provide appropriate care (Lang, 1989).

In any society, the experience of illness is strongly influenced by culture, because it is an intimate part of the social systems of meaning and rules for behaviour (Kleinman et al., 1978). It is seen therefore, that illness is culturally shaped, in that how the individual perceives, experiences and copes with disease is based on the individual's explanations of sickness within his or her own socio-cultural setting. These explanations are specific to the social positions that people occupy and the system of meaning they employ (Eisenberg and Kleinman, 1981). Because illness behaviour is derived from an individual's culture (Pfifferling, 1981), it is not surprising that there can be marked cultural and historical variations in how disorders are defined and coped with (Long and Long, 1982). The variation may be equally as great across ethnic, class and family boundaries in one's own society (Suchman, 1965). As well, doctors' explanations and activities, as are those of their patients, are culture-specific (Freidson, 1970), consequently, there are many views to explain the behaviour of illness.

In the clinical setting, ethnographic research is the most appropriate approach for clinicians such as nurses and doctors who are concerned with clinical questions and desire analysis and resolution of clinical problems (Kleinman, 1977). An ethnographic approach in the clinical setting provides knowledge about two socio-cultural systems, client community, and the health care system. It is as participant observers, working within the health care system, that anthropologists learn the health care structure, its modes of operation, professional roles, and the goals of the organization along with its individual members (Burdett and Godkin, 1983).
Ethnographic Study in Nursing

Although ethnographic study has been used widely in anthropology, especially in the field of cultural anthropology for nearly a century, it is essentially a new approach in the field of nursing research. It has really only been in-vogue for nurse researchers during the last two decades with those early researchers only becoming aware of ethnographic field study methods through attendance at anthropology and transcultural nursing courses. The ethnographic method has been of particular interest to a growing number of nurses because of the considerable degree of focus which allows the nurse to gain more personal and comprehensive accounts in the area of patient care. Ethnography as methodology therefore, is pertinent to the nursing system and is one that is helping nursing professionals to reach into the patients' real world (Leininger, 1978).

As well, there are an increasing number of nurses who are aware of the cultural differences in patients under their care (Chao, 1984). With this awareness has come a greater demand for literature from studies done on patients from those various cultural and subcultural groups which highlights the need for more substantial information to be made available to nurses in order for them to get down to the business of understanding and caring for humans.

It is seen therefore, that in nursing studies, the ethnographic approach is viewed as being most useful since it allows the nurse researcher an insight into the way in which that activity occurs (Field and Morse, 1985). Using participant observation in this approach, allows the nurse to adopt the function of 'being there', thus taking an important step in bridging the gap between patient and nurse researcher. "It is also a timely method to use as nursing moves closer to knowing human beings in personalized, direct and intimate caring ways" (Leininger, 1987, p.34).

As a result of the considerable interest shown by nurse researchers in ethnographic fieldwork, many publications concerned with those studies have become available. From these works, two distinct types of ethnography have been identified as being of particular interest to nurses. These types are, mini ethnography and maxi ethnography (Leininger, 1984).

The mini ethnographic study is defined as a small-scale study focusing on a specific or narrow area of inquiry. The study however has limited scope and includes a partial study and analysis of social structure, world view values, and environmental factors, whereas the maxi ethnographic study, having been defined as a large and
comprehensive study of general and particular features of a designated culture, is where nurse researchers focus on obtaining the broadest and most detailed view of health and illness of the living people of a particular cultural or subcultural group. Examples of what would be termed as maxi ethnographic studies are, "Study of the health-illness system of Spanish-Americans in an urban community" (Leininger, 1968); "Health and illness beliefs and practices in a southern Italian community: An ethnographic study" (Ragucci, 1974); "Observations of a health and healing system in a Papago community" (Aamoldt, 1976); The Cancer Unit: An ethnography" (Germain, 1979); and others. In these studies, nurse researchers set their goal as the description of an entire culture.

As indicated here, an ethnographic approach which developed from the implications of the symbolic interactionist view of human behaviour, would be the best way to understand the meanings of experience in cancer patients. From symbolic interaction, methodological principals guide the researcher using an ethnographic approach. Firstly, the meaning of the experience of having cancer must be understood from the perspective of the participants. To accomplish this, the researcher must 'take the role of the other' (Taylor and Bogdan, 1984) and understand the world from the patients' perspective, being both a participant and an observer of the participants of that world. Therefore, the behaviour and action thus observed must be understood at the behavioural and symbolic levels. Secondly, meanings are derived through social interaction, in that the researcher understands those meanings by sharing the knowledge available to the participants of that setting (Van Maanen, 1983).

Ethnographic Study of the Thai Cancer Patients

THE COLLECTING OF DATA

In order to study the meaning of illness as perceived by Thai cancer patients, the 70 bed Cancer Hostel which provided temporary shelter for cancer patients whilst undergoing cancer treatment, was selected as the setting for conducting a field study.

In studies conducted in natural settings, it is rare for all planned aspects of data collection to proceed smoothly and in this section some of the unexpected issues which were encountered will be described. As well, the mechanics of data collection used in this study will be covered by general descriptions of unstructured interviews.
Initially, it was planned to study the daily life events of all cancer patients within the Cancer Hostel setting, with the study being conducted over a six month period from early July to late December 1990. In reviewing the aims of the study and deciding that I needed to understand the entire daily life activities of those patients, changes to my original plans would have to be made. This necessitated that I cover a broader perspective than initially envisaged and would include covering the patients activities at the treatment centre, as it was there that they would spend the greater part of their day. However, within the first week of my fieldwork, I found that Cancer Hostel patients, as well as being referred by Siam Hospital, were also referred by Bangkok's three other cancer treatment centres. With one of these centres being part of the Cancer Institute in the heart of Bangkok, the others were located in two of the capital's major public hospitals, and whilst close in terms of distance, factors of time spent in travelling and being caught up in Bangkok's notorious traffic would preclude me from covering those settings. As well, the expected complications in gaining entrance to all centres would create problems that I did not need at that time. It was therefore decided to follow only those patients referred by Siam Hospital.

In deciding to follow only those patients who were referred by Siam Hospital, I was at no less an advantage, as this hospital referred the majority of Cancer Hostel patients, that is, in the 6 months prior to the commencement of this study, Siam Hospital referred 133 cancer patients whereas the other 2 hospitals and the one institute referred 90, 59 and 13 patients respectively.

It was also more convenient, as the two institutions, Siam Hospital and Cancer Hostel, were within close proximity of each other. As well, being a staff nurse of Siam Hospital, where I had worked for more than fourteen years, would give me ease of access in my efforts at gaining permission to conduct my study in both settings.

Another change to the original concept of my field study was the role to be adopted whilst I was with the cancer patients. This change is covered in detail in Chapter 4 of this study.

Research Techniques

PARTICIPANT OBSERVATION

In this study, participant observation was the major data gathering technique employed. The selected technique is aptly described by Becker and Geer:
By participant observation we mean that method in which the observer participates in the daily life of the people under study, either openly in the role of research or covertly in some disguised role, observing things that happen, listening to what is said and questioning people, over some length of time. (Becker and Geer, 1969, p.322)

As participant-observer in fieldwork, there are several roles which ethnographers may adopt through the course of their studies and depending on the settings provided, may move from one to another. Junker (1960, p.36) for example, describes four different types, complete participant; participant as observer; observer as participant; and complete observer. Decisions about what role to adopt within the setting will depend on the purpose of the research and the nature of the setting. For example, in the complete participant role, the ethnographer's activities are wholly concealed. Here, the researcher may join a group as though he or she is an ordinary member but with the purpose of carrying out research as in the case of Rosenhahn who became a pseudopatient in a number of psychiatric hospitals (1982), or the researcher is already a member of the group that he or she decides to study, as in the work of Holdaway (1982) on police in a busy, urban police sub-division, of a large American city.

As ethnography is based on the underlying criteria that what people say and do is consciously and unconsciously shaped by the social situation, being on site is the "sine qua non of ethnographic research" (Smith, 1979, p.341). The strategy of complete participant might seem very attractive and may be the only strategy by which the data required can be obtained. However, Pollert found that her complete participant role as a female factory worker would limit her actions in her quest to optimize data collection possibilities. She wrote:

Had I got the job, the advantages of experiencing for myself what it felt like, and possibly becoming very close to a small work-group around me, would have been heavily out-weighted by the disadvantages of restricted movement, abiding by the rules preventing entry into other departments (without permission), and losing the privileges of the outsider, of speaking to other employees in the factory, including chargehands, supervisors and managers (Pollert, 1981, p.6).

In contrast to the complete participant, the complete observer has no control at all over those being observed. These observation may take place through a one-way mirror, or in public like that undertaken by Karp (1980) on the public sexual scene in Times Square.
Although the role as complete participant and complete observer can minimize problems of reality between the ethnographer and those being studied, there may be limits on what can and cannot be observed and the questioning of participants may be impossible. More than that, by adopting either of these roles alone would prompt serious ethical questions raised by such covert research. Researchers then, are presented with a number of ethical decisions and various moral alternatives when deciding on the manner in which knowledge is to be gained.

It has been shown that undercover or covert methods may jeopardize the goodwill between researchers and informants whilst damaging professional reputations and could lead to the cutting off of research areas. As well, there is already a social back-lash against social research (Taylor and Bogdan 1984).

Others believe that knowledge gained justifies any method used. Douglas (1976) likened it to a dog-eat-dog situation where lies, evasion, and deception are the norm and researchers must adopt these practises to gain information where it is of practical social benefit and feel fully justified in doing so.

Some informants advocate a right not to be researched with the exposure of knowledge remaining the prerogative of the informant. As well, they condemn those who would harm or infringe on their privacy and well-being. In matters of ethics then, researchers must endeavour to counterbalance the multiple responsibilities accorded their profession in the pursuit of knowledge. These responsibilities extend to their society, their informants and themselves.

Taylor and Bogdan (1984) argue that there are situations where covert research is both necessary and justified, depending on the subject studied and resulting intentions. Citing an example where research tends to focus on the powerless within our society, they suggest it may be warranted to study the more powerful by using covert means. It is however, unethical and difficult to justify the employment of these methods purely for one's academic gain.

Because the disadvantages of covert research are its limitations and the fact that it can also become ethically problematic, most field research involves roles somewhere between participant-as-observer and observer-as-participant. Whether the distinction between these two roles is of any value remains a point of conjecture. In fieldwork,
when the active involvement in peoples' activities is essential to acceptance, it may be as Taylor and Bogdan (1984) suggest, that because participant observers walk a thin line between these two roles, there are clearly, times when it is best not to be accepted as a genuine member of the setting or group.

Decisions concerning the role adopted in a setting will depend on the purposes of the research and the nature of the setting. For example, Ragucci (1976) adopted the role of a graduate student residing locally for her study of the health beliefs and practices of women in an Italian-American enclave. She had decided to adopt this role even before making rental provisions for an apartment in that area and thought that this role would assist in establishing rapport and a relationship of mutual trust and respect with her informants.

In another study, Germain (1979) assumed a nursing role in her study, "The cancer unit: An Ethnography" with the role allowing her to ease in and out of the patient care situation. Gaining the acceptance of the regular nursing staff, she was able to talk openly with patients, families and staff members in the data gathering process as well as encountering their unsolicited views and feelings. Being able to adopt the various roles in addition to that of the Anthropologist-Researcher, played a large part in the gathering of quality information from this subculture.

McIntosh (1977), in his study "Communication and awareness in a cancer ward" adopted the role of researcher and restricted his efforts to observation and the taking of notes. Initially, he found it difficult to become immersed as a member of Ward 4C culture. Later, he found that instead of being the detached onlooker, he joined in on patients' communication as if he was one of them. It was with this approach that he was able to enter into their world and become accepted as a member of their group.

Overall, McIntosh found it to his advantage not to get involved with questions concerning patient illness and warded off any attempt to do so by 'simply pleading ignorance'. As well, by adopting this non-committal stance in his dealings with them, it quickly became apparent that he was not 'an appropriate source of information' and not a member of hospital staff. As the study by MacIntosh was "to investigate the way in which patients conceive of, and respond to, their illness and to examine the structure and organization of what was communicated to them" (McIntosh, 1977, p.13), getting involved with questions of that nature, the objectivity of the study would ultimately be effected.
Therefore, in collecting data for the present study, I adopted the role of a nurse who was on study leave for higher degree work and who was interested in studying the patients of Cancer Hostel. The establishment of this role allowed me to ease in and out of the patient care situation, not only in the Cancer Hostel environment, but also in the ensuing accompaniment of patients to and from Siam Hospital to cover the treatment centre situation.

Importantly, living in Cancer Hostel enabled me to become part of the situation being studied in order to feel what it is like for patients who stay in the hostel whilst being involved in a cancer treatment programme. "Such participant knowledge on the part of people in a setting is an important resource for the ethnographer" (Hammersley and Atkinson, 1983, p.106).

INTERVIEWS

A second major technique of collecting data open to me was the use of interviews, wherein the notion put forward by Chenitz was thought as being rather apt, in that, "In all interviews, the basic assumption is that the respondents 'are telling the truth' about themselves and their world as well as speaking the truth about their beliefs and perceptions about their world" (Chenitz, 1986, p.80).

For those conducting ethnographic interviews, Hammersley and Atkinson (1983) suggest that ethnographers do not decide beforehand the questions they want to ask, though they may enter the interview with a list of issues to be covered. They further suggest that on different occasions, or at different points in the same interview ethnographers may use the non-directive or directive approach in their mode of questioning, depending on the function that the questions are intended to serve.

On the unstructured or non-directive interview, Swanson (1986) suggested that the investigator who is new to this method may use an interview guide containing a set of brief, general questions, a topical outline, or a major theme in order to clarify the general area about which the respondents will be asked.

In this present study, in-depth, generally unstructured interviews were used. To answer the research question, a non-directive question approach containing general questions was employed with the focus being upon the patients' experiences of illness. The direct questioning approach was used only when it was suspected that informants had been evasive in their responses.
During all interviews, I neither told the respondents that the major focus of the study was on cancer, nor did I, at any time during the study, introduce the word cancer. Instead, I presented myself as being primarily concerned with their symptoms, the effects of illness and treatment, and their social situation, and so on. As was the case with McIntosh (1977), the patients were told the truth about the study as explicitly as possible without mentioning cancer.

As I was very soon to learn, other situations would arise, wherein by the very nature of the subject being discussed, the conduct of the interviews became potentially tricky, and as encountered by McIntosh (1977), a situation developed whereby the patients, in the course of these interviews, asked me about their illness. To answer in any way, other than as reported by McIntosh would effect the integrity of the investigation, I therefore, intended to follow the example set by him and "plead ignorance."

SUPPLEMENTARY DATA SOURCES

The supplementary data which I called on to help me understand the patients at the centre of my study and the institutions in which I studied them, came from a variety of sources which included, life histories of multiple case studies; analysis of case studies; patient's records; photographs of my field trip and some social events; patient information literature including instruction books, articles written by staff and the histories of both institutions.

Recording

FIELDNOTES

Ethnographic fieldnotes are traditionally the recording of observation data. The importance of fieldnotes is as Hammersley and Atkinson reported, "A research project can be as well organized and theoretically well informed as you like, but with inadequate note taking, the exercise will be like using an expensive camera with poor quality film" (Hammersley and Atkinson, 1983, p.146).

Since fieldnotes provide the raw data of participant observation, Taylor and Bognan (1984) suggested that researchers should strive to write up the most complete and comprehensive fieldnotes possible. In fieldwork studies, if the researcher simply
writes down what he sees and hears, he will more than likely end up with masses of documents which may be next to useless. "Among other things, the fieldworker will have to ask what to write down? how to write it down, and when to write it down" (Hammersley and Atkinson, 1983, p.146).

Notes were taken from the very beginning of this study whilst engaged in the general observation of those to be studied, whereby the impressions of what I saw, heard, felt, smelt and thought were recorded. In fact, note taking was well under way long before the task of reporting on actual events that would become part of the data collection process. These early notes recorded the experiences encountered in gaining entrance to conduct the study.

Short notes were taken at the scene of the study as I was afraid of later forgetting the significant information coming from those events. I noticed however, that most of the participants showed signs of becoming uncomfortable, with one female patient expressing her feelings about my note taking by remarking, "It is as if you are finding fault with us." As well, I felt that my actions of writing quick notes whilst with the participants, actually distanced me from them.

Subsequently, notes were not taken during any further conversations or during any participant-observer interaction. Rather, comprehensive, detailed descriptions of all events and conversations were written down as soon as possible after they occurred, thus limiting distortion through delay from incident to notation. I therefore resorted to tape-recording most of those events and later, usually in the evening, I would replay the tapes and transcribe the spoken word directly into my fieldnotes.

TAPE RECORDINGS

For individual and group interviews, tape recorders were used, primarily to reduce the tension that one would most certainly experience during an observation and note taking exercise such as this. More importantly, the use of a recording device provided a more complete, concrete and detailed record than could not be gained through the sole reliance on fieldnotes. However, as a tape recorder could not capture the non-verbal aspects and features of the physical surroundings, descriptions of those aspects and features were then recorded as a supplement at the end of the recording session.
It is realized that in using a tape recorder the researcher runs the risk of making the respondents feel uncomfortable, behave atypically, or worse, refuse permission for such recordings to be made (Hammersley & Atkinson, 1983). Efforts in preventing these situations developing, were directed at providing a truthful explanation to the informants for the use of such a device, in that it was simply an aid to handwritten notetaking, as well as stressing that total confidentiality would be maintained in all subsequent recalls of their accounts. To assist in overcoming the problem of the tape recorder becoming a barrier between researcher and informant, a small, pocket portable, voice activated mini-cassette recorder was used.

The recorder was kept in my rather large handbag with a small sensitive microphone clipped onto its strap. This 'set up' allowed me to record any interview with patients in any setting without creating an uncomfortable situation for the patients in their conversations with me. As well, the taping of group discussions provided significantly more detail than if I had relied on taking notes at the end of proceedings. It was also more convenient for me to record my personal feelings of some of the important things that I observed at the actual time of their happening and not have to worry about missing such information as I would with post-event note taking.

I found that most patients accepted this technique and that during those times spent in conducting both individual interviews and group interviews, patients were relaxed and showed no signs of the tenseness that had once existed.

**Ethical Considerations**

The ethical principles influencing the present study were adapted from those suggested by Diener and Crandall (1978) in dealing with the ethical problems involved in ethnographic type research studies. These ethical issues were, informed consent; privacy; deception; use of knowledge; altering the culture; intervention and advocacy; and benefit to those studied.

**INFORMED CONSENT**

Although I was allowed to follow the patients into both Cancer Hostel and Siam Hospital, the fact that I had been given permission to be present at some of the most intimate moments of their treatment was not taken for granted. Therefore, I made a point of personally asking permission of my informants for me to be with them during the course of my involvement in their day to day activities. I also realized that my presence with the informants may have some effect on their daily activities, such as
when following them to the radiotherapy treatment rooms where my appearance could bring a feeling of embarrassment to the patient, especially in cases of those receiving treatment to sexual organs.

As well, I was aware that my interviews of patients concerning their experiences of a life threatening illness like cancer, might expose them to stress and a risk of harm. Considerations were therefore made to cover and prevent any adverse eventuality that might arise, notably, the causing of patient distress, in which one was ever mindful of the need for diplomacy and sensitivity toward informants. Therefore, clear explanations about my study and its implications were given to all informants before commencing an interview. Moreover, it was accepted that it remains the patient's "right not to be researched" (Sagaring, 1973) as well as being able to withdraw, refuse to continue or participate with any part of the interview.

Requests for patients to participate in the study were made on a person to person basis with verbal agreements being sought in which a willingness to be part of my interview programme were expressed.

PRIVACY

To guarantee confidentiality of data and anonymity of informants, I assured those taking part that when referring to any part of their recorded accounts, only pseudonyms would be used. As well, I reassured them that only I would have access to the data and that all the evidence would kept in a secure place. Although, I was sure that all patients were well protected by their pseudonyms, I was not so sure that it would be the same for the two institutions and the staff who figure in those accounts. I realized that with the specific characteristic of both institutions and the specific nature of the jobs performed by those select group of staff informants, pseudonyms would be quite easy to track down. Although there were no demands from either institution to cover up their identity, I decided, only after much self debate, to use the fictitious names as appear throughout this study.

DECEPTION

In this study, deception was knowingly used to soften the impact of my questioning and to reduce the chance of hurting the patients by referring to the true reason for my study, in that I did not directly inform the patients that I wanted to study their cancer illness experiences. This was done, as I felt that by introducing the word cancer when
outlining my study intentions as well as bringing it into our daily interviews and conversations, would cause the patients undue distress. As well as reducing the chance of hurting the patients, my act of concealing my true intentions also served as a mechanism to avoid being diverted from my study aim by any unsolicited questioning and the like. And so, I simply told them, as previously outlined, that I did not know about their illness and was primarily concerned with their symptoms, the effects of their illness and associated treatment, and the social ramifications resulting from such an illness.

USE OF KNOWLEDGE

As a result of the patients co-operation and their willingness to share their experiences, this study has provided valuable information on the matter of Thai patient’s experiences in their efforts to combat cancer illness. It is hoped that this information will fill the gap in existing knowledge concerning Thai cancer patients and in so doing, provide a basic account from which Thai health care providers may understand Thai cancer patients from a Thai cultural perspective.

INTERVENTION AND ADVOCACY

The ethical researcher should consider a non-invasive approach toward the host community, but in a sense, that really only gives a limited perception of the world of the people studied. Realizing that my mere presence in the field would inevitably influence the group under observation, I took steps to minimize the chances of my presence having any lasting effects on those in the study, as well as not getting involved in any activity that could cause lasting change.

Although, I tried to intervene as little as possible into the everyday life of the people I studied, there were some situations where it was impossible for me to remain a neutral observer. This was especially so when patients requested my aid or when I found patients to be in a very stressful and difficult situation and that the situation would deteriorate if I did not help. Pleasingly however, I found that my intervention greatly benefited my fieldwork study. After assessing that I had genuinely helped them with their problems and not done just for personal or professional gain, patients let it be known within their circle, that I was a kind and helpful person. The perception held by patients that I was one who was concerned with their well-being not only did a lot to build on the already established rapport, but also encouraged them to actively participate in my study.
Data Collection Procedures

Most of the ethnographic data introduced here was collected between July and December 1990. Within that relatively short period, numerous research techniques were employed in which participant observation and unstructured interviews were the most often used. Systematic fieldwork was carried out at Cancer Hostel, the patients’ shelter and at Siam Hospital, the treating institution. Intensive fieldwork was spread over the time spent in following patients through both institutions. Fieldwork, with few exceptions, was conducted on a daily basis with the only breaks being in times of sickness or the one week rest period, mid stream of this study, when I returned to Australia to consult my supervisor.

Efforts at gathering data were initiated a short time prior to my gaining permission to enter the study environment. I had gone to the waiting area of the Radiological Department of Siam Hospital, where the patients usually gathered before being called in for treatment, as well as visiting the rest area used by most Cancer Hostel patients at times when they were free from treatment activity. Without informing anyone of my intentions, I casually strolled into those areas (like any other visitor) and took a seat amongst them whilst listening to what the patients were talking about. Most patients paid scant attention to my being there with them as those areas were close to rather busy thoroughfares and many people would walk in, sit down to rest, before walking out again. Some patients assumed that I was 'one of them' and it wasn't long before one female patient asked me "Where is your disease"? and although I told her that I was not a patient, she still maintained "I think that you are a patient waiting for treatment." However, we continued with our rather one-sided conversation and I listened attentively as she spoke of her illness and her treatment.

Being amongst the patients 'in those places' and 'at that time', allowed me to become accustomed to the ways that cancer patients talked about their disease. This would become an extremely important asset for me, in that it allowed me to be familiar with the language they used (in terms of different social groups) and later on, when formally entering into the field situation, to help me communicate with them and ask the appropriate questions in a manner that was acceptable to all.

One week later, after being granted permission to carry out fieldwork in both institutions, I made a series of visits to Cancer Hostel and Siam Hospital for the purpose of becoming familiar with the physical setting, the staff, and the patients' routine of everyday life. Although I was soon to gain the required permission, this approach to familiarization would continue for one month, in which I would spend nearly every day
getting to know the workings of Cancer Hostel and the hospital's Radiological Department, places where patients found themselves as participants in the life activities of both institutions. As well, during this one month period, an effort was made to become accepted and to gain the trust of the patients as well as my own personal adjustment into an unfamiliar world, the world of Thai cancer patients.

After one month of "being with" the patients and satisfied that I was able to merge into the patients' world, consultations were held with my (Thai) supervisor, who was formally accepted as a qualified academic to supervise my collection of data, and who also agreed that it was time to move on to where the more general questions of the study were formulated and translated into a framework of more specific questions under topic headings. This outline served as a guide to the type of research information to be collected on each patient. And so, plans were made for a more systematic and intensive approach toward the research and a more intensive collection of data on the patients began.

New patients who were admitted to Cancer Hostel, were selected into the study, there being no set criteria for the inclusion of each patient other than the researcher's own ability to cope with the personal resources of time and energy. Therefore, in order to acquire as much knowledge as possible of what happens to the patients from the broadest possible range of patient informants, I willingly 'signed on' as many new patients as thought to be realistic in terms of my physically being able to cope.

Once patients were selected, information from patients', files including demographic, socio-economic, diagnosis, treatment plan, treatment scheduling and staff records were collected and rough research plans for following each Cancer Hostel patient from arrival until discharge were set down. Interviews were scheduled for the early days after arrival as well as on the day before discharge in order to compare any detected change in patients' attitude on completion of treatment.

All other interviews conducted during the patients' stay, varied in terms of frequency and individual situation encounters. Patients who received only teletherapy treatment were interviewed less frequently than patients who underwent teletherapy combined with brachytherapy. In cases where patients suffered severe effects from treatment, they were interviewed more frequently than patients who were less severely affected.
However, most patients were interviewed on at least three occasions during their stay in Cancer Hostel. Interviews of others involved with the patients during their time as residents of Cancer Hostel, such as, relatives and friends; fellow out-patients; and staff of both institutions, were interviewed whenever possible, depending on their willingness to co-operate.

Time spent in each interview varied and depended on the topic, the physical and psychological readiness of the patient and other respondents and the willingness of those respondents to co-operate.

The places where interviews were conducted, depended mostly on the activity of the patient at the time, or as on a number of occasions, whenever and wherever respondents, such as doctors, nurses, technicians and so on, could be 'nailed down' long enough to take part.

Some interviews were conducted 'on the run' whilst respondents were at their work or treatment site, and which saw informal interviews with the busy doctors being conducted whilst they were attending to such thing as the applicators prior to radiation therapy or during the conduct of a tumour clinic session. As well, patients were interviewed whilst waiting for treatment or the results of pathological tests and so on.

The overall period of time spent in conducting the more intensive interviewing and patient observation lasted for nearly four months with twenty one patients being selected during that time to become my case studies.

The number of patients under study at any one time varied, and whilst I began with just three patients, I continued to pick up new participants until towards the middle of my planned time in the field, the numbers had increased to ten. In this middle phase of my stay, patient numbers remained fairly constant and as I had a target date for completion of my fieldwork, I was able to judge as to when the cut-off date for enlisting new participants would be. I would also begin to decrease the number of patients by not replacing them as they completed their treatment, until the day when I would see my last patient leave for home and which preceded my exit from the field by a few short days.
One patient, Mr. Adoul, who had been involved in my study, remained and continued to receive treatment, having been removed from his programme due to the side effects of combined chemotherapy and radiation treatment. Mr. Adoul was scheduled to complete his treatment a fortnight after my withdrawal from the field environment.

Towards the end of the study, I spent less nights in Cancer Hostel, and more in the nursing dormitory of Siam Hospital as well as gradually withdrawing from my everyday activity with the patients and spending more time engaged in other tasks such as, transcribing information from the patients treatment files into my own journal and the like.

Data Analysis

Qualitative methods are designed to explore unstructured data in ways that preserve its richness and context (Richards and Richards, 1991). In analyzing this kind of data, the researcher needs to organize those unstructured data that will allow process into concepts, then concepts into relationships. That is to say, in analyzing qualitative materials, the researcher is trying to find underlying patterns that when joined together make sense out of those materials.

Although there are different ways that qualitative research data can be analyzed, the common processes which is involved in all analyses, are collecting and bringing together all the data documents; coding or indexing field data under various indexing categories; searching for actual words or phrases and the like in the various segments of the documents; use of indexing as well as text search as a basis for finding passages of text and ideas in them; making notes and memos about emerging ideas and theories as the project develops; re-organising and extending the indexing as the understanding and theorising grows (Richards and Richards, 1990).

As initially planned, the mode of data analysis would be explanation building which aimed to describe lived experiences of Thai cancer patients. By examining the data without preconceived notions or any particular theoretical stance, and through a process of data analysis, discovered patterns, themes, and their relationships which yielded theoretical propositions of cancer illness as perceived by Thai cancer patients.
The analysis of data documents in this study would prove to be rather complicated. I had returned to Australia soon after leaving the field environment to commence the rather daunting task of transcribing information from the large number of recorded cassettes collected throughout the field research period. These transcripts were then assembled along with all other written accounts in preparation for analysis.

Initial efforts to index documents by hand were abandoned as these documents contained large amounts of information, with my fieldnotes filling three large exercise books along with the many thousands of pages of transcripts of unstructured interviews taken from hundreds of audio cassette and micro-cassette recordings. After reviewing the task at hand and noting the volume of data to be analyzed, it was realized that it could take an extremely long time to complete. Manual methods were found to be inadequate which meant that another method would have to be looked at.

On searching for any computer software that would help to speed the data analyzing process, it was found that there was no suitable, reasonably priced Thai software available. Therefore, if I decided to use English language computer software, all documents would have to be translated from Thai into English before being typed onto a computer, a rather formidable task. This option seemed far worse than the former option of managing the data by hand, as translating word for word, would (based on a trial run with interview notes from just one respondent) take more than a year. It was fortunate that among the software available for qualitative analysis, one package, NUDIST™ (Non-numerical Unstructured Data Indexing, Searching and Theorising) computer software, developed by Richards and Richards (1990), could be applied for use in the analysis of data documents which were recorded in other languages as well as in the English language.

NUDIST had the advantage of using documents that are typed onto the computer as well as documents that are not typed onto the computer (online and offline) which allowed me to make only partial translations of selected documents into English which were then typed onto the computer and used as online data. Documents that were left in their original Thai form were introduced onto the computer as offline data. Being able to use the original documents in their written Thai form, not only kept the richness of the original meaning, but also saved a great deal of time.

Like any other code-and-retrieve software package used for qualitative analysis, NUDIST can read online text and allows the researcher to label numbered "text units" with codes. All online text that has been labelled with a code, as selected by the
researcher, can then be retrieved at will. However, there are a number of beneficial differences with NUDIST over other programmes and all manual methods. These differences include unlimited retrieval of indexed documentary material with no limit to the number of times a rich passage of text can be indexed or on the number of indexing categories that can be used. All retrievals are recorded showing exactly when and how it was retrieved as well as showing text of online retrievals with all cross-referencing, thus allowing efficient management of even the most complex material.

Another difference, is that retrievals can be made whether or not the material is typed onto the computer. This allows indexing and exploration of any unstructured text and can therefore accept offline fieldnotes such as books, tapes and a variety of other highly complex sources. Documents that are not typed on are divided into nominated units, for example, pages; rows; or paragraphs and so forth and indexing entered as for text units of online documents. Retrieval of this offline data gives the same indexing information but does not allow the display of those source documents.

Complexity of the indexing data base presented no problem, as NUDIST can handle from the normal code-and-retrieve programmes to the highly organized and complex tree structured indexes. This presents a number of advantages, in that indexing concepts can be organized and managed as theoretical systems as well as managing a large number of indexing codes in a rational and logical way.

In supporting the development of theories from the recorded data, commentary text can be added to and and deleted from any index category. NUDIST also adds its own comments automatically, thus giving an idea on the development of ideas in the research project.

The NUDIST indexing system welcomes inspection and exploration of itself and not just the indexed documents and can be modified at any time which allows the user to shuttle around within the indexed documents and their category nodes for a broader look at emerging ideas.

A unique feature of NUDIST is that it combines exploration of indexing information with searches for words or patterns occurring in the text and by combining this feature with the node building operation, the user is given a powerful text search tool which can be pattern or concept-based.
As NUDIST is designed to handle as many of the different qualitative approaches to unstructured data analysis as possible, it was selected as the appropriate tool for data analysis of the present study.

PROCESS OF DATA ANALYSIS

At the time of analysing the data, there was no one available who was conversant with the workings of the NUDIST software package. Therefore, much time was devoted to the self-study of the accompanying manuals. After spending some time reading the reference manuals in conjunction with hands on practice by running a trial document with the software package to get the feel and to see how NUDIST works, the data analysis of the present study was ready to begin.

Twenty-one documents, compiled from transcripts of individual and group interviews with patients of Cancer Hostel, still in their Thai written form, were then given pseudonyms in preparation for introduction into the NUDIST programme. Three of the more comprehensive case studies were selected and translated from Thai into English and following the reference manual instructions, these translations were then typed onto the computer and introduced into the NUDIST programme as online data. The remaining case study files, along with my fieldnotes, were not translated but introduced into NUDIST as offline data.

After introducing the data into NUDIST, individual indexing categories were created as suggested by both online and offline data documents. After a pattern emerged, I began to collect categories into clusters under specific headings which were manipulated and linked to other categories and sub categories in a tree-structured index system. For example, the category "in hostel" which concerned patients' accounts of their reason for being residents of Cancer Hostel (Figure 1), was linked to two sub-categories, "have shelter" and "no shelter." The sub-category "have shelter" was linked to sub-sub categories of "own home" and "provided." The sub-sub-catagory "own home" was linked to sub-sub-sub-catagories "tiredness", "expenses", "dependence" and "no rest." The sub-sub-catagory "provided" was linked to sub-sub-sub-categories of "tiredness", "expenses", "dependence" and "inconvenience".
The NUDIST tree structuring system allowed me to understand the concepts and themes that emerged and the relationship of these to each other. For example the structure of "in hostel" indexing tree (Figure 1), reflects the relationship of the sub categories and sub-sub categories which provided me with an understanding of the situation of patients who were admitted to Cancer Hostel. As well, it not only allowed me to manage the large amounts of emerging information, but also, the management of my emerging ideas from that information, and to use those ideas as further data within the project.
Planning the Ethnographic Report

On completion of data analysis, preparation for writing was planned. This step involved NUDIST’s tree indexing system which greatly facilitated the process in giving me the advantage of being able to arrange information in a specific order and which corresponded to the plan for writing this report. NUDIST’s tree-structuring facility proved to be an extremely flexible and accommodating method for organizing knowledge, whilst maintaining simplicity and understanding of the structuring of the tree which facilitated the writing of this ethnographic report.

All tree structures, which were the heart of my analysis and report writing, were printed out and organised into seven major area of concern. These areas covered, the researcher’s experiences in the field; patients’ health-seeking process; patients' lived experiences whilst in Cancer Hostel; patients' experiences within the treatment setting; the sufferings, anxieties, stresses, and concerns that beset the patients and their mechanisms for coping; as well as the patients' given meaning of cancer. These seven areas became the seven major chapters, designated as chapters four to ten and which formed the core of the data analysis and report writing of this study.
CHAPTER 4

GETTING STARTED AT CANCER HOSTEL

Introduction

In 1989 when I first embarked on a course for the degree of Doctor of Philosophy by research, I already knew that my field of research would be devoted to the study of the cancer patient. Although I had over fourteen years of experience with cancer patients in the clinical setting, there still remained a feeling of being distant from them as it seemed that when expressing an interest toward their illness 'whilst showing the uniform', barriers would go up and I would be left with more questions than answers. As well, the practice of withholding the true diagnosis from the patients in Thai society meant that I was to become even further distanced from them as I was compelled to uphold the wishes of the doctors and continue to deny the patients requests for more information concerning their illness.

As for my intended study, I really had no idea what I would elicit from my experiences with cancer patients in an institutional setting whilst taking the role of a nurse researcher and not that of a nurse actively engaged in nursing care. However, with so much to be done in the preparation stage, the task of gaining entrance, the obvious change to my personal life and the inherent concerns, and so forth, prior to entering the field, there was little time left to sit back and contemplate as to what would eventuate during the time spent in a new environment. And so, having already made the decision to study the cancer patients who were residents of Cancer Hostel, a temporary charity shelter for needy cancer patients whilst receiving treatment, I began to make arrangements for the task of gaining entrance and to conduct my project in that and other institutions.

Gaining Entrance

My experiences in gaining entrance into my field research, were by Thai standards, quite unique. Though my early plans, were to me, quite straight forward, things do not always go as planned and I was to learn that the system of personal introduction would play a most important part in helping me to gain access into my chosen field of concern.
No one had attempted to study the patients in the manner that I proposed and early mention of actually wanting to live with those being studied, almost spelt the end even before I had started. The negative stance adopted by those to whom I discussed my desire to live with the patients at Cancer Hostel, can best be shown by relating some of the responses of my close friends. Some of those responses were, "Are you crazy, can you really stand the smell?"; "Can you live with all that disfigurement?"; "Do you have any other way that you can do this study?"; "You are very brave to be doing this. Aren't you afraid of being amongst those with a contagious disease?"; and "It would be OK if it was just two or three patients."

Things did not look encouraging. However, intervention on my behalf by Mrs. Pranee, a personal friend and one who had initially expressed doubts that I would be allowed to conduct the study as intended, would smooth the way for me to gain permission of entry and to carry out my studies as originally planned. My friend, a senior nurse in the Radiological Department and with whom I had worked on many occasions, would save the day. It is good to have friends.

I realized at that time, that no one had attempted to gain entry to this institution based on a personal introduction technique, and although it was not intended to approach the question of gaining entrance by means of this technique, it is my firm belief on looking back, that it is highly doubtful that entry would have been gained if it was not for the timely advice and personal contact in my favour, displayed by that senior nurse.

My first day back in Thailand, after spending one year studying in Australia, was one of excitement, and far from being exhausted as one would expect, I was alert and eager, and ready to begin the task that lay ahead. I had gone early that morning to the Radiological Department of Siam Hospital to see my old friend, Mrs. Pranee, as I wanted to enlist her help and advice on how to go about gaining permission to conduct my research at Cancer Hostel. Mrs. Pranee suggested, that because Cancer Hostel was (then) under management of the Cancer Society, I should present my case to Dr. Rut, the secretary of the society who was also a senior doctor in the Radiological Department of Siam Hospital. However, although "the doctor is a kind and understanding person, he can also be a difficult man at the same time", my friend then suggested that it would be easier for me to approach the doctor if she went to see him beforehand and told him about my proposed study, and so, Mrs. Pranee asked me to give her a day or two to put forward an outline of my intentions.
Being eager to get into my study as soon as possible, I returned to the Radiological Department the following day, where I was told by Mrs. Pranee that she had already gone to see Dr. Rut and that it would be alright for me to see him. I wasted no time and went straight to see the doctor, knocked on the door of his office, opened it and upon entering, introduced myself to Dr. Rut who greeted me with "Oh!, you're the one that Mrs. Pranee was talking about yesterday" and without further ado, went straight into a discussion concerning my case. My appointment however, went smoothly and on concluding our short discussion, verbal approval was given for me to proceed with my proposed field of study in Cancer Hostel.

It seemed that Dr. Rut did not fully understand all aspects of my field study, as after I had presented my proposal he quickly fired off a barrage of questions interspersed with pessimistic statements, "How many cases do you want to collect?"; "What is the tool that you will use to measure your observation?"; "What statistic will you use to analyse your data?"; and "I don't think that your participation with the patients in Cancer Hostel will allow you to get any more information than by using a questionnaire", and so on.

The doctor did not show any interest in discussing with me the methodology that I would use. However, at the end of this rather cheerless discussion, the permission that I sought from him was given, along with the expressed expectation that, "At least the patients will have the benefit of your being there, in that they will have a nurse available to help in situations that might eventuate." The meeting concluded with the doctor asking that a formal request be submitted to the president of the Cancer Society outlining my intentions. Later on that day, I presented Dr. Rut with my letter of request addressed to the president of the society, along with a letter from Deakin University approving my study and a copy of my research proposal.

In our resulting further discussion, it was agreed on my using Cancer Hostel as a 'base' for my study. Our discussion then centred around my proposal to 'live in' with the patients to which the doctor showed some degree of uneasiness and suggested that:

You can go to interview the patients at Cancer Hostel at any time and if you want to spend time in observing them, you can stay there for as long as you want. However, I cannot give you permission to live at Cancer Hostel because we really have no facilities available or which are suitably equipped for you to carry out your study.
The doctor went on to tell me that he had already contacted the housekeeper about my going there and had given brief details on what I would be doing. As well, he made particularly sure that I understood the present situation with the housekeeper and that I should acknowledge that Miss Yarchai was not a trained nurse. In further explaining about that position and how the situation had come about, Dr. Rut showed that he was rather concerned that Miss Yarchai was not a trained nurse and he again stressed that I should not expect Miss Yarchai to perform the role of a perfect nurse in looking after the patients.

After all that effort, my request to 'live in' at Cancer Hostel in order to be close to the patients' routine of daily life, was rejected. Therefore, in order to have maximum exposure to life situations as they occurred, I elected to live nearby in a place which allowed me to have easy access to the patients and to be with them from their waking hours to bed time. And so, I decided to live with my friend in the nursing dormitory at Siam Hospital which was really only a short distance away and depending on the traffic, the time of day and the mode by which one chose to travel, took from ten to thirty minutes to make the trip.

Having been in the fieldwork situation for about two months and travelling 'to and fro' on a daily basis, permission to 'live in' at Cancer Hostel was finally approved and I was allowed to take up residency in the hostel, being allotted a small staff room which had been used to store the personal effects of one of the staff members.

The way in which permission was gained from the president of the society is yet another example of how personal introduction was again to help me. When accompanying the patients to the hospital for their daily treatment session, I had a chance meeting with my old boss, a former director of nursing of Siam Hospital and one whom I held in great respect. Whilst we were chatting, she asked me about my study and on hearing that I had not gained permission to live at Cancer Hostel, told me she would ask the cancer society president, who happened to be her good friend. Not long after that meeting, the housekeeper told me that the president had asked her to arrange accommodation for me if I wanted to live in Cancer Hostel.

Early in this study, it was my intention that the daily life events of all Cancer Hostel patients would be followed. This idea was dropped however, as it would entail commuting between the four cancer institutes as well as monitoring the non treatment hours of those patients spent at the shelter. In concluding that I could ill afford the time spent in the continual shuttling between the various centres, it was decided that I should follow only those patients who were referred for treatment by Siam Hospital, as it was this hospital
that referred the majority of patients who were to become residents of Cancer Hostel. It was also more convenient, as the two centres, Siam Hospital and Cancer Hostel, were within close proximity of each other. Also, because I was a staff nurse of Siam Hospital, to follow the patients in a setting in which I had already worked for more than fourteen years, gave me certain advantages and made my work in the field much easier than would have been the case if I was not a member of the hospital's staff.

The problem of how to gain permission to carry out that part of my fieldwork which would allow me to accompany the patients into the clinical setting, was overcome in the early days of my study. Firstly, I had to find out who in fact it was that I should be contacting in order to request such permission. That part of my problem was partially solved after completion of the "grand tour" (Spradley, 1980) carried out over a two day period of the first week of my participating in the field.

I began my "grand tour" by accompanying the patients on the first of my many trips in the open-sided truck which would take us to Siam Hospital. During the tour, I followed the patients as they made their way to one of the three locations from where they would receive their treatment. All treatment locations were in the 'A' building of Siam Hospital and occupied the first, sixth and basement levels of that building, where I was able to make contact with some of my friends who worked in those areas and find out which department controlled those areas and who I should seek out to ask. So now that I knew who controlled the treatment areas, it was simply a matter of writing up a formal request and submitting it to the right person, or so I thought.

If I was to follow the patients activities into all three places, permission would have to be sought from two separate departmental sections, the Radiological Department, which controlled the sixth floor and basement level treatment centres, and the Nursing Department which, controlled the first floor treatment centre. My requests therefore, would have to be directed to the heads of both those departments. Not long after preparing the necessary written requests, I was ready to tackle the last two hurdles of gaining permission, that if successful, would allow me unhindered access to those three areas of concern.
Because there was no system in place for me to make an appointment to see the head of the Radiological Department, it was a case of where I had to simply knock on the door and wait to be called in. But to my disappointment, at my first attempt no one was there, and as it would do no good to sit around and wait, I decided to complete some other business in another part of the hospital and try again later.

After a number of unsuccessful attempts to catch Dr. Vena, the head of the Radiological Department, at her desk, my perseverance eventually paid off and I was able to meet her one afternoon. I introduced myself and submitted my formal letter of request to conduct my research in the hospital division under her control along with a letter from Deakin University and a copy my research proposal. After becoming aware that I was studying abroad, the doctor showed that she was willing to discuss my plans with me and that she was happy to share some of her experiences of her own studies overseas. Our discussions covered all facets of my fieldwork and after two and half hours, verbal permission was granted, after which Dr. Vena indicated that she would support my project and would inform the staff in her unit about my study.

As I would later learn, the staff were not informed of my project and on a number of occasions I was asked if in fact I did have the necessary approval to be in that area. This did not cause me any great concern however, as I would simply introduce myself to those in the areas that I was concerned with, outline my reason for being there and reassure them that I did have permission from the head of the Radiological Department.

It is interesting to note that Dr. Vena had previously refused many projects using questionnaire based research methods, to be conducted within her unit. She explained that some questions, such as, "Do you have any of the following symptoms whilst undergoing radiation treatment: bloody stool; cystitis; or loss of appetite?", led the patients into worrying that they may develop one or more of those symptoms and caused them to run away from the treatment. The fact that she agreed with my methodology and was satisfied that I would in no way harm the patients, was definitely a contributing factor in my gaining entrance.

Permission to conduct field research in Ward 6 on the sixth floor was granted by the director of the Department of Nursing, Siam Hospital. After my experiences in gaining entrance to other areas of concern, it was for me, comparatively easy to seek and be granted permission to conduct my project in the Ward 6 area. It was a mere formality for me to submit the paperwork required by that department in order to gain the necessary acceptance. Although my request was submitted with some degree of surety, it was
nevertheless, processed like any other request and acceptance was gained on the merits of the proposed study in its own right. The passage of my application through the various channels within the nursing department would have been eased somewhat because of the fact that I was a staff member and the approving authorities were those people with whom I had previously worked or had been responsible to in my days as a staff nurse.

The staff of the nursing department were quite helpful in their assistance to me during this early stage and offered their full support at every level and in any matter I wished to follow. From some of the comments concerning my selected methodology however, it was clear that most were unfamiliar with the ethnographic approach in studying the patient. It was also clear that there was a degree of scepticism among those who remarked on the suitability of such an approach and who thought that research was a questionnaire from which discernible patterns of response would give almost immediate answers or feedback from those under research. For some, research was the use of tested instruments, statistical formulas and numerical computer analysis and so forth, whilst for others, research was some kind of experiment where known substances were added together in precise quantities, mixed, heated, and so on, with immediate results forthcoming from any subsequent analysis.

However, there were some nurses who felt that my research approach of 'participant observation in the natural setting' would give me a great opportunity and a better way to understand the cancer patients. As well, they showed by their excitement that they were interested in what I would find in my study and were eager to know the results of those findings.

**Settling-In: The Field Situation**

Getting settled in Cancer Hostel and Siam Hospital was not as easy as I thought it would be. From the outset, it was my intention to 'live in' at Cancer Hostel in order to be close to the daily life routines of the patients, but after being rejected in my earlier attempt to gain approval to do just that, I decided to live with my friend in the nursing dormitory of Siam Hospital. Travelling time between the two locations took from ten to thirty minutes depending on the traffic conditions, so it seemed logical if not convenient, that this was the ideal place to stay.
As a single nurse, I had lived in that dormitory for over five years and had only given up my room there one year before commencing my present doctoral study and was a direct consequence of my becoming a newly-wed. I was aware that there was no way for me to ask permission to live in the dormitory, as there were no rooms available and there were long waiting lists for single new-comer nurses. As well, I knew that hospital rules stated that only single nurses were legally entitled to live in the dormitory, being part of hospital's welfare entitlements extended to them.

It was true that most staff, including the dormitory housekeepers, knew that I was living illegally in the dormitory, but it seemed that no one minded or were overly concerned with my presence and the subject was never raised by any of those who knew of my situation. My being there was of no special circumstance, nor was it a case of being extended the privilege of being 'over-looked' that was not offered other nurses in similar circumstances. There were those nurses who did much the same as I, in that the married nurses who were on late duty, preferred to stay over-night in the dormitory rather than attempting to go back home late at night.

Many of my friends who lived in the dormitory suggested that I should stay with them, that there was room enough for one more. I had however, already accepted the offer of one of my close friends, who although having only a very small, single room, it was convenient for me to stay with her as she was quite often on night duty and we were both able to carry out our set daily chores without bothering the other. On those nights that we were both in, my friend would offer to sleep on the floor, but I would insist that she needed the rest more and I would sleep on a sheet that I would spread on the floor alongside her bed.

Although this was not the ideal situation as far as 'living with the patients' was concerned, every effort was made to be with them during their active hours, and as I lived within the grounds of Siam Hospital it was not at all difficult to put into practice. Rather, it gave me more of an advantage in participating in patients' every day life, both at Cancer Hostel (shelter) and Siam Hospital (treatment centre). That is, in the mornings, instead of taking a bus to Cancer Hostel, I took the vehicle that would be used to transport the patients back to the hospital for daily treatment, and I would catch them during their final preparations in readiness for the move to the hospital.
As well, when following those patients undergoing intracavitary treatment and where the treatment was scheduled to begin very early in the morning, my living in the hospital's nurses dormitory gave me the added convenience and less tiring option of meeting those patients at the treatment centre.

My daily ritual of travelling in an attempt at 'being with' the patients was to continue for about two months and lasted up until the time when I would finally be granted permission to 'live in' at Cancer Hostel. I was to find however, that in relation to having close access to the routine of daily life, that it did not really make much difference whether I lived in Cancer Hostel or stayed at Siam Hospital with the only noticeable change to my daily activities being of a personal nature.

To 'live in' at Cancer Hostel, required a little more effort on my part and was less convenient than what I had become accustomed to. The room to which I was assigned had been used by one of the Cancer Hostel staff to store items of personal equipment and was nearly the same size as my friends room back at the hospital dormitory. The similarity between the two however, ended there, as my new abode was soon found to be in need of some running repairs. The door latch was broken and the fly-screens that were in position (3 screens for 5 windows) were holed. However, after the door latch had been replaced, the holes in the screens closed with clear tape and the removal of some of the equipment, the room was then ready to be 'my other shelter' whilst engaged in the conduct of my fieldwork.

My activity schedule with the patients on the day I moved into Cancer Hostel, was no different than any other day, and in the late afternoon, as I had done on many other occasions, I followed the patients to the transport provided to take us to Cancer Hostel. The only difference this time, was that I carried a small bag containing my personal belongings.

Although, I had not informed the patients that I would go to stay at Cancer Hostel, it did not take much guess work on their part to conclude that I would be staying with them and when they saw me walk into the waiting area with my little bag, one of the patients came up to me and said, "You are going to stay with us tonight, aren't you?" Some of the patients showed signs of gladness that I would be staying with them and offered their
good wishes, as one female patient remarked "It's good that you can stay overnight with us, now you don't have to worry about travelling back to the hospital alone at night. It's not really safe for a young woman." Another patient thought it good for an entirely different reason and commented, "Now the staff and their families will have to feel *kreng jai* [self effacement, humbleness toward a social superior] toward you and not make all that noise at night."

On arriving at Cancer Hostel, I reported to the office and informed the housekeeper of my presence, then made my way to my room and after spending some time cleaning up my 'living space', I rejoined the patients, and as usual, participated in their late afternoon activities until half past seven that evening. Later, instead of going back to Siam Hospital, I retired to my room at Cancer Hostel.

Settling-in to the fieldwork situation was far from being pleasant and un-problematic, as it took me at least a month to become conditioned to the everyday routine that I encountered. In the early days of my fieldwork I felt uncomfortable in being in close contact with the patients on a round the clock basis, along with the smells and the bodily appearance of the patients as well as the smells of soiled linen and the putrid smell of the malfunctioning sewerage system of Cancer Hostel, constantly tested my resolve to stay in the field environment with them.

Being with patients also caused me to have feelings of embarrassment and was quite discomforting for me during the early days of my study and although these feelings would decrease somewhat as time went on, they were never to leave me entirely.

One afternoon, at the very beginning of my time with the patients, I joined them on one of their trips from Siam Hospital to Cancer Hostel, sitting alongside them in the back of the open-sided truck. Whenever the truck stopped at traffic lights along the way, I felt that people from other cars were looking at me and expressing their feelings of pity as they most likely thought that I was one of the poor cancer patients. At that time, I felt most uncomfortable and did not dare to look out for fear of making eye contact with those people. I felt like to shouting at them, "I am not a cancer patient." This feeling was to subside however, and I found later, that I was able to ignore peoples expressions and began to feel much more comfortable in my chosen situation.
Role and Relationship in the Field

In a broad sense, field research is the study of people acting in the natural courses of their daily life. Despite the entry into ethnographic fieldwork of what was called the 'social science' tradition (Kroeber, 1955, p. 307), the field situation remains a fundamentally human one where the kinds of data obtained, the willingness to provide information or to hold back, and the types of interpretations that are made, are all influenced by the personalities of the parties involved and how they perceive and deal with one another.

I realized early in my study that simply being with the patients all of the time, does not necessarily guarantee an acceptance into the lives of those being studied, as one must gain their trust and allow time for them to express their feelings in relating experiences of what Thai people have labelled a taboo subject, that of 'cancer illness'.

My success in establishing a rapport and a relationship of mutual trust with the Cancer Hostel patients, depended largely on the role that I adopted, my attitude toward those being studied, and to a significant degree, my physical appearance or 'dress sense' of which I was constantly aware.

Long before gaining entry into Cancer Hostel, I had decided to adopt the role of graduate student and not as eventually decided upon, a nurse who was interested in studying the meaning of illness of the patients in that institution. The reason behind my initially not wanting to reveal that I was also a nurse, was that I feared the patients would ask me questions about their illness which would possibly effect the meaning they assigned to their illness and would obviously flavour the very subject that I wanted to study.

My intended role however, was changed to a nurse who was on study leave for higher degree work and who was interested in studying the patients in the Cancer Hostel environment. The reason for this change was that whilst I was in the process of gaining permission to carry out fieldwork in both settings, I found that the doctors and nurses who were either my friends or work associates and who I had not seen for a year, would come up to me and welcome me back and ask the numerous questions one would expect in this situation.

On this, I began to wonder how could I keep my position as a nurse a secret from the patients who were to be told something quite different. It was then that I decided that it would be in my best interests if I did inform the patients of my nursing position.
However, I would not inform the patients that the major focus of my study was on cancer, instead, I would inform them that I was concerned mainly with their symptoms, the effects of their illness and treatment, their social situations, and so on.

Another example which showed me that I could not control the situations that developed in the field, was when Miss Yarchai, the housekeeper, introduced me to some of the hostel patients during my first visit. This unscheduled event of being introduced, put me into a completely unexpected situation and was one that I did not have full control over.

I had gone to Cancer Hostel to see the housekeeper and to introduce myself after permission for me to study there had been granted. The main reason was for me to acquaint myself with her and to get to know a little about the place where I would spend a good deal of time in conducting my field study.

After a long talk in the late afternoon, I bid my farewell and began to leave, but the housekeeper insisted on showing me around, saying, "It will take only a few minutes." Although I had told Miss Yarchai that I didn't want to meet any of the patients at that time, as I was not yet ready and which Miss Yarchai seemed to understand, things would go a little astray. On being led around the various facilities we found our way into one of the accommodation rooms where I followed Miss Yarchai in making our way through the patients living area and where to my surprise, I was introduced to a number of patients and as some of them had been referred from Siam Hospital, she informed them, "This is khun payabarn [nurse] from Siam Hospital, she has come here to look after you. If you want any help you can ask her."

Once in the field, I found that my decisions to approach the research study as I had anticipated, had been the right ones. At first, the patients could not understand why a nurse would want to spend so much time with them at the hostel, just to learn about their illness and treatment. Some were more perplexed than others, and would ask, "Why do you want to study us?"; "Didn't your school teach you about our disease?" I also had to contend with some of the patients asking me about their illness.

Being aware that if I attempted to answer their enquiries in any way, it would affect the integrity of the investigation, I therefore, as suggested by (MacIntosh, 1974), pleaded ignorance. This tricky approach seemed to work however, as in the later months of my stay with them, the 'old hands' would inform the new arrivals that, "This nurse does not
know about our disease. That's why she is here with us. She wants to learn from us." I also found that patients were eager to give information to me as they felt that my success in the study relied on their responsive attitudes.

This initial belief of the patients, that I knew nothing about their illness and treatment and therefore wanted to study them, was really to work to my advantage as it would stop them asking me about their illness. Instead, patients provided me with a wealth of information free from inquisitive diversions that would almost certainly have plagued me if I had adopted a more knowledgeable role. Also, there were many patients who expressed an excitement that the experiences of their illness were considered as being worth studying.

It would be untrue to say, that by pleading ignorance to patients questions as well as denying my knowledge of cancer illness, would necessarily see the patients continue to believe me or ease their inquisitiveness away from the subject. On the contrary, as I very soon found out, in that after replying to their questions about their illnesses with my stock answer of, "I don't know", most patients would show through facial expressions that they did not really believe me. In fact, some patients would confront me directly with, "I don't believe you. If a nurse doesn't know, who else would know." Some patients even assumed that I knew everything, but did not want to tell because I was afraid of hurting them, whilst others, although not voicing their disbelief, would show in their eyes that I was rather less than convincing.

Most of the patients however, did not attempt to press me further for the truth, but rather, they distanced themselves from me and tended to watch me, gossip about me, or even to eaves-drop on my conversations with other patients or staff members. There were a couple of patients who tried to play tricks on me with the hope that I would unconsciously reveal my knowledge about their illness that I was hiding from them. Patients would employ various ruses in trying to elicit a response to their enquiries and 'Playing Peter against Paul' was one of the more common approaches.

An example of their cunning ways was when I was confronted by one of the patients, who rather nonchalantly mentioned, "One of the nurses told us that you have a lot of knowledge concerning cancer and that we would be able to ask you anything we like
about it." Some patients would use a different angle, such as (whilst indicating one of the other patients) engage me in conversation with, "I think that woman has mareng [cancer]. Does she have any chance at all to survive?" and "I don't think that radiation therapy will cure that woman of mareng. What do you think?"

The mistrust shown by those very people I was attempting to study was unnerving and made me feel rather uncomfortable. Luckily for me however, this situation was to last for only a short time during the initial stages of my being with the patients and was especially felt in the first month of my field study.

My attitude toward those being studied was another important factor which helped me gain mutual trust from the patients at the centre of my work. I realized early that this study was very important, not only for me, but also for cancer patients themselves, wherein this study would provide me with what could be my only chance to answer those questions which had tormented me for so long and which have been mentioned earlier in the introduction to this work. It would also, by understanding "how people live and cope with cancer", provide a basic but most important span of knowledge on the provision of care for cancer patients, of which very little was known within the ranks of the professional health care providers and within Thai society at large. My early enthusiasm to conduct this study remained with me and brought a positive attitude toward my fieldwork. It was this positive attitude that continually renewed my strength and conviction to complete this study, as well as allowing me to overcome the difficult situations as they arose.

My choice of dressing in an unobtrusive style of clothing, was successful in decreasing the 'social distance' between myself and the patients. This method of 'fitting in' was adopted, as within Thai culture, the standard and style of dress is one of the criteria which divides the social classes. To put it another way, by dressing in the way of middle-class professionals, I would be considered as an 'outsider' by the patients of Cancer Hostel. Of course, the thought of entering the field as a uniformed nurse was never entertained and although it was realized that a great deal of prestige would be attached, it could be seen as a symbol of control and order, a condition one would not want to encourage.

Although my style of dress was seen by most as being an appropriate form of gaining acceptance and help me move more freely amongst those being studied, not everyone agreed with my candid approach. At least one doctor felt that it was not the right method to use in conducting research in the clinical setting. My conclusion for this thinking came after a conversation with one of the practical nurses, when after observing one of the
patients in consultation with Dr. Nit, the practical nurse, who worked with the doctor, came to me outside the doctors room where she informed me that:

Dr. Nit has asked me about you and wanted to know who you were. This is because he had seen you accompanying many of the patients when they were visiting him. He initially thought that you were one of his patient's relatives, but today, when he saw you with another patient he began asking questions about you. When I told him that you were a nurse and have come here to conduct your research, he asked why you were dressed in a casual style of dress and not in a more formal style as other researchers and remarked that it was very difficult to distinguish me from the patients relatives. He also enquired as to whether or not you had asked permission to conduct research at the Radiological Department.

After informing the practical nurse that I was indeed permitted to conduct my research within the Radiological Department, and that I had gained that permission from the head of the department, she told me that she would inform the rest of the staff. My next 'accompanying' visit to the Radiological Department was without any form of inquisition into my being with the patients in my normal mode of dress, and although seeing Dr. Nit working within the department, he made no sign of acknowledging my presence and as I was rather pressed for time, I left it that, happy in the knowledge that my style of dress had at least allowed me to look like the family group of those cancer patients whom I was studying. It is acknowledged however, that it was rather odd for a Thai nurse to be in such a clinical setting in any form of dress other than regulation nursing uniform, neat business suit or similar standard 'civilian attire'.

Patients' Attitudes Toward the Researcher

Patients would stay in Cancer Hostel for approximately five to six weeks according to the prescribed course of radiation treatment, which meant that when I commenced my fieldwork, there would be some patients who had almost completed their treatment, whilst others were well into the course of treatment and yet some patients would be in the same situation as I, and in having just commenced their treatment, they would be the new residents and together, we would be 'the new kids on the block'.

Given the preceding situation and patient awareness of my nursing background, my entry into the patients community was accorded rather more privilege in comparison with patient newcomers. Patients showed their respect to me by calling me khun (a term showing respect) and spoke to me in a very polite way. This is related to the Thai person's perception that every existence within society is arranged hierarchically and that 'being
Thai, they are taught at a very young age, the appropriate behaviour to deal with such hierarchies. Patients therefore, recognized that their social status was lower than that of a nurse and they were always mindful that the nurse be accorded the appropriate respectful behaviour due to that station. However, I later made it known to them that my nursing status meant nothing in relation to the present situation of my being with them as participant observer.

This 'abdication' was accepted by the patients who rather than call me by the title khun, reverted to calling me Noo (used normally when referring to a child or younger person), or my real nickname of Mu (pig), a sign that they had accepted me as being of equal status. (It should be noted that Thai people, very rarely in their lifetime, will ever get called by their real birth name by family, relatives or those who are close friends. As well, in Thai usage of nicknames, a pig is regarded as being cute, or a sign of good health and is never used derogatorily).

There were of course, some patients, who from the very beginning of their stay, tried to build up a relationship that I perceived as being an attempt to gain favour, whether it be for special consultation on their illness or simply to be in a more favourable position to hint at borrowing money or some other form of material support.

Other relationships developed that were thought of as being more genuine attempts at forming a friendship based on the respect that they felt for me. This relationship extended to their wanting to be helpful toward me in fields other than simply being a supplier of information concerning their own illness. One example comes to mind, and here, one has to remember that for the purposes of my study at Cancer Hostel, I "knew nothing about their cancer disease" and that I was with the patients "to learn from them." Mrs. Wandee, one of the cervical cancer patients and one who was particularly friendly toward me, came up to me one morning after receiving intracavitary treatment and was quite concerned that I had not visited her the night before during her treatment preparation. She said:

Why didn't you come up to see me last night?, you missed an opportunity to learn about cancer. There was a patient there, her name is Sao and she knew a lot about cancer and if you were there with us, she could have given you a lot of interesting information that would enhance your knowledge about our disease.
One can only guess at what qualities the patients saw in me that would appear to them as being worthy of their friendship. Although patients opinions differed in detail and covered a considerable range of reasons, they seemed to agree on the one thing, "that I was a good person as I was very kind and I had a good heart."

During my stay with the patients at Cancer Hostel, a number of patients would come to me and (in their rather secretive manner) tell me that other patients had been talking about me:

... in a nice way though Mu. They said many nice things about you. They said that you are different than other nurses in that they feel comfortable when you are with them and that they can be open in their discussions and dare to ask things that they cannot talk about with others. Many others agreed and said that some of the other nurses were arrogant, but you weren't. You are easy to get along with.

At other times, patients would talk to me directly and offer thanks for helping them in the most basic tasks, but which for them were rather special. Mrs. Boontoung stopped me one day and thanked me for arranging it so that she could see the doctor a number days beforehand. She told me:

Noo, you were very kind to help me the other day, I'm glad that you were here and could spare the time to take me to see the doctor and to help me buy the drugs at the pharmacy. It's good that you give your time to us, we really enjoy it when you come to talk to us in our rooms and that you are there with us when we are receiving treatment. It makes us feel good when you talk to us, it makes us feel better. We know that it must be difficult for you to live with us and we are grateful that you do not object at being near us, it makes us feel warm.

The older patients were particular warm toward me and often mentioned that they felt the same way about me as they felt about their own children. Others would express their thanks for the little jobs that I would do for them, such as helping with their being exempt from the treatment fees (which I did without their knowing, or so I thought, as I was later to learn that they had found out about this help), or helping the husband of one of the patients to be admitted to the hospital for an operation. One of the older female patients was touched that I had gone to the nurses canteen and bought her favourite food som tum (a savory of sliced green paw paw, mixed with a sour condiment). As well, the fact that I was able to suggest to her, a source of financial support also endeared me to her.
It was certainly gratifying to know that the patients felt highly of me and particularly so when some patients called me by the name jai bun (meritorious heart; kind-hearted). This small recognition was reward enough in itself. It was clear to me that the patients' responses toward me personally, were influenced by their responding to the research being done on them, that is, their feeling toward me definitely effected the interview. In my early interviews, conducted with patients who were just beginning their stay in Cancer Hostel, I found them to be impatient, with no concentration, withheld certain information, as well as showing signs of not being willing to give information and were rather careless in their answers to my research questions. However, amongst my initial frustrations, there were some brighter moments and I found that there were patients who showed their liking of me from the very first interview meetings. This of course, was most pleasing and from their willingness to be part of my interviews from the very beginning, came the opportunity to record the feelings of patients who were recent arrivals within such an institutional setting. It was however, only during subsequent interviews, that I felt there was a gradual development toward a trustful and mutual relationship with most patients.

Patients who thought of me as kin and who accepted me as luk larn (niece; grand daughter, depending on relationship of speaker), felt certain obligations toward me. As well, this acceptance as kin had a significant effect on their behaviour during my interviews with them. These effects were both positive and negative, the positive side being that those patients accepted the responsibility for my success in this study and therefore took serious steps at providing me with accurate and correct information. In doing so, patients were ever mindful to ensure that I did not miss even the slightest detail in any item of information that they offered. An example which can best illustrate this, is the time that I was preparing for a group discussion with three patients, held during a lunchtime break between treatment sessions. Sitting down beside Mrs. Lumpoo, I made myself comfortable having already ensured that the micro-cassette recorder was running and that the small condenser microphone was securely clipped to the shoulder strap of my hand bag. Before commencing the actual interview discussion, I opened, as usual, with our customary conversation on the days events and the effects that their treatment was having on them. Having completed a only few brief sentences, Mrs. Lumpoo stopped me and in her most concerned manner, asked "Have you got your tape-recorder going yet. Don't forget to turn it on, you may miss something important."
Another reason why patients were glad to be part of my study was the opportunity to return the favour for something that I had done for them. And so, in order to express their gratitude, they too would become willing sources of reliable and accurate information. Examples were often seen of their diligence in providing as much information as they could and their willingness to give as much of their time as possible to ensure that nothing was missed. One common example of the latter, was that on many occasions, they would volunteer to skip their meals so that unfinished interviews or discussions were not interrupted and could continue until completed. These offers, of course, were never taken up and I would ensure that patients were never put in a position where they would miss or be late for a meal on my account.

On the negative side, patients in their efforts to provide a more intelligent account of their illness, would often use a more technical explanation than that which had been used in previous interview sessions. These patients had obviously felt, that for me to understand the cause of their cancer illness, they would have to be more intelligent informants by searching for knowledge from other sources and not from their own understanding. This 'overstating', resulted in the 'flavouring' of their answers to my questions, which of course, was not the type of information that I was after and would colour the research result if left unchecked. Therefore, I found it necessary to explain to them again, the objectives of my study, emphasizing that the patients' own information was the more worthy knowledge for use in the study. An example of their efforts to be more intelligent informants came during an interview with Mrs. Wanna, where the topic of our conversation was centred on her perceived reasons for her having contracted cancer:

R: What do you think was the cause of your getting cancer?
Mrs. Wanna: I think it is caused by the . . . err, err, . . . abnormal cell, which is . . err . . growing over and over [multiplying].
R: And how does it grow?
Mrs. Wanna: It grows from inside. . . uhm . . I don't know.

From this dialogue, it can be seen that although Mrs. Wanna had been informed of the biological reason for the growth of her cancer, she could not tie it in with any of her previous knowledge and was only repeating what had been told to her. Through the way in which she answered my questions, which was not her normal manner of speaking, I knew that she was trying to help me by providing (what was to her) a more knowledgeable explanation. Without trying to appear that I was judging her or knew that this information was not from the heart, I thought it necessary to explain, that it was important for her to give me information which came from her own understanding and not what had
been passed on to her by other sources and that her own story was more important than any biological explanation, because from her own story there might come some information that was not known about and which could benefit all cancer sufferers.

**Researcher's Attitude Toward Those Being Studied**

It was my intention to conduct my research in a manner that would not jeopardise my position as an impartial observer, and not one where special relationships would form. This aim was adhered to right up to the end of my stay with the patients at Cancer Hostel and my friendship was shared equally with all patients, regardless of how differently patients may have viewed my being with them. Any efforts at forming 'special' friendships of any kind during my time there, were instigated by patients. There was one big advantage however, of having some patients warm to my caring more than others, in that I found these patients to be the better informants.

Some of the patients actions were rather annoying as on some occasions, patients would indicate that they really did not want to talk to me. Their reasons for those actions, although not given directly, were perceived through indirect statements, that at times were rather difficult to comprehend and would take the form of an aside, such as when Mrs. Sumarng told me, "I don't like her (referring to Mrs. Mann whom I had just spoken to), she is very smelly, when she sits down she opens her legs to let the smell go." This form of insincere gossip was common place and it was annoying to hear that some held others in such low regard for such minor breaches of protocol, that they would endeavour to hurt them through this rather silly form of gossip. At other times, when I really did not have the time or the inclination, patients would try to take advantage of my office as a nurse and ask me to purchase drugs and the like for them, and would show some form of anger when I declined to do so. There was a constant feeling on my part, that I was being tested by some of the patients to see if I could be of some sort of assistance to them. A feeling that I really did not relish.

On the other hand, I would often become frustrated at not being able to help the patients more than my position of impartial observer would allow, but I also realized that to weaken once and openly give my assistance, would mean that I was obliged to help all and sundry in the same manner. And so, my help for the patients was limited to what I could do for them without them knowing (or what I thought they did not know).
However, on withdrawing from the field, I was at last able to help in some small way and having decided that my help would best be suited by helping the institution that helped the patients, I donated eight clocks to be fixed to the walls of the patients’ rooms.

Not all interaction with the patients involved the sombre reporting on a rather cheerless set of life events, there being quite a number of more lighter moments with most patients showing a rich sense of humour, and others, with their 'rural brand of naivety', often giving cause for me to laugh within myself.

One such occasion, quite often comes to mind. After lunch one Saturday, I came up to and stood at the bedside of Mrs. Sumarng and struck up our normal tete-a-tete conversation. Whilst we talked, I looked around at her few belongings neatly arranged on top of the small bedside cupboard, when my eyes suddenly fixed on one small bottle of kemycetin eye drops, which she had placed away from her other things. I asked her, "Why do you keep your eye drops over there?" She answered, "I wanted to keep it cool." I then asked "How does it keep cool if you leave it out there?" Looking at me as if I was a bit demented and pointing at the ceiling fan, she explained, "That fan keeps it cool. As the label says, "Keep in cool place", At home we have a refrigerator, but here we haven't got one." It took all my efforts to hold back from laughing at such a wonderfully naive answer, which of course, nearly killed me in the process. This episode still brings tears of joy to my eyes when I think or talk of (what was and still is for me) "that rather unique experience."

As with most fieldworkers, my experiences with cancer patients at Cancer Hostel were many and varied. In many ways, the Cancer Hostel patients were a group of people who would "take you in, care for you, and treat you as kin." They shared with me what they had and were willing to talk with me about what they knew and felt.
CHAPTER 5

CANCER AND HEALTH-SEEKING

Introduction

In any culture, when human illness occurs, one of the important and most widely studied issues is the way in which that particular culture influences and shapes the way the illness is experienced. Although human knowledge and beliefs about health and illness differ radically from one culture to another, they remain of significant importance and are taken seriously by most within all cultures. This knowledge plays an important part within any cultural setting, and is paramount in influencing and shaping the responses of the individual's life and world.

Although this study focuses on the immediate experiences of the Cancer Hostel patients who were undergoing treatment, the story of their pre-institutional experiences as part of their health-seeking process was considered to be one of the important themes, and if followed, would lead to a fuller understanding of the patients' experience of cancer. As well, it would provide knowledge of how patients respond to cancer illness prior to becoming institutionalized and coming from within a society where there were more than one health care system available from which they could seek help for their health problems. This knowledge of course, would reflect Thai cultural responses to cancer, which as in many other cultures, represents extreme examples of uncertainty in a life threatening situation.

This chapter then, explores the experiences in the progression of unfolding evidence associated with illness and health-seeking from the early symptom experiences to the experiences encountered in Cancer Hostel. Therefore, by studying the cancer patients experiences within the Thai cultural setting and documenting the stories flowing from their individual encounters and their efforts made in relation to the health-seeking process, it is hoped that patterns that emerge will guide Thai health care providers to an understanding of Thai cancer patients interpretations of, and their responses to illness, in their search for help.
Responses to Early Symptoms

The conceptual elaboration of the health-seeking process is the "natural history of an illness episode" (Chrisman, 1977, p. 354). This process focuses on the individual and the ways in which the health care system influences behaviour. For Cancer Hostel patients, the health-seeking process began with the evaluation of early symptoms with most patients not taking their early symptoms seriously and it was only after the persistence of those symptoms that they became aware that something was wrong.

The realization that things were not as they should be, forced most patients into taking some kind of action. For most patients, the initial reaction to persisting symptoms such as leukorrhea, sore throats or itchy rashes, was to resort to some form of self-treatment. This self-treatment included self-medication, non-medicinal self-treatment, and no action.

Among those patients who decided on self-medication, there were many who chose to purchase modern drugs from the local drug store, whilst others bought herbal medicines from either the local drug store or a local herbalist. Mr. Prasert, a cancer of the tonsil patient told of his initial efforts at self-treatment:

At first, I thought my sore throat was a sign of inflammation, so I went to the drug store where the druggist told me that it was tonsillitis and gave me a drug for the treatment of that condition. After taking it, the swelling to the left side of my throat went down, but the right side remained the same. I didn’t do anything about it because I felt no pain. It didn’t bother me, so I left it alone.

It is common in Thailand for those having a practical knowledge of appropriate drugs used to treat a wide range of complaints, to have access to those drugs by purchasing them from the local drug store. This situation has developed because of the government’s policy which allows even the most modern therapeutic drugs to be dispensed by pharmacists without prescription. Also, pharmacists and druggists do not hesitate in recommending drugs to all and sundry. With this convenience, a man with a fever for example, is much more likely to treat himself with antibiotics purchased from the drug store, rather than go through the time consuming and more expensive consultations with medical practitioners.
The herbal druggist was another outlet often chosen by the patient for the supply of alternative medicines which were preferred by many patients for use in self-medication for a large variety of illnesses. Mrs. Boontoung, told of her early actions in treating, what she thought to be, a minor complaint, "I didn't suspect anything, I thought it was only normal leukorrhea, so I went to buy yamor (home made herbal medicine) for leukorrhea from the local herbalist."

There were some patients who did not revert to the use of medicines in their efforts to be rid of their symptoms. These patients chose a course of non-medicinal self-treatment, which for some, included a form of diet restriction, whilst others preferred simply to drink holy water, their belief being that these non-medicinal means would promote the healing process.

Some patients however, decided to combine both self-medication and non-medicinal self-treatment in order to better the therapeutic affect. Mrs. Utorn, one of the cervical cancer patients stated:

... Leukorrhea, I then went to buy drugs to treat myself, I later haemorrhaged. ... there is a doctor, but I didn't go to see him. I didn't think it would be like this, I felt a little better after taking the medicine. But when I ate hot, spicy food such as preserved fish it made me hot and itchy, so I stopped eating it. After that, I only suffered from a white, watery discharge.

For others, who on noticing the first symptoms of their illness, it was a case of not perceiving them as being serious, but rather, interpreting them as being part of normal body functions and continued to go about their daily lives whilst learning to live with their discomfort. Mrs. Boontoung, a cervical cancer patient, told how, "It began with leukorrhea, I had it for long time, ever since I gave birth to my youngest daughter. I did nothing at that time though, because I did not think there was anything wrong."

Some of the patients claimed that shyness and a fear of rejection kept them from coming forward to seek advice. Mrs. Lumpoo, a vulva cancer patient explained:

At first, I didn't tell anyone, my daughter, my son-in-law, not even the doctor. ... at that area [genital area] there was an itchy rash which became ulcerated, it was sheer agony, but I tolerated the discomfort. ... I felt shy about letting anyone see it and I also had a fear of being rejected if any one knew about it.
Poverty was another important factor which influenced the patients in their health-seeking behaviour. An example of this was the case of Mrs. Nuchin, a patient suffering from cervical cancer who related how, after first noticing that she had leukorrhrea, did nothing, but went about her daily housework routine, as well as working hard in the rice fields close to her village. Through further questioning, it was found that the underlying reason for her non-action, was in fact one of not having the money to purchase either the modern drugs or herbal medicines that might have improved her condition.

It is interesting to note, that none of the patients indicated that they sought professional medical care from a medical doctor on first noticing their symptoms. The two most frequently given reasons for this were, firstly, that the early symptoms were not severe and were not indicative of an illness that required medical care, as well as the patients having the knowledge of home remedies that would correct those symptoms; and secondly, the medical care service was located far from their place of abode, making it rather inconvenient and costly for them to seek help from that source for an illness which they thought could be effectively treated by various home remedies.

The Consultations

As documented earlier, many patients sought to treat themselves for as long as they could, coping with their debilitating symptoms through belief and trust in ancient herbal remedies or in the more modern drugs bought readily from local suppliers, or as it was for some, trust in some form of self-induced restrictions to their diet. A clear example as to the extent to which patients would revert to self-treatment was revealed when Mrs. Utorn, a cervical cancer patient, reported,"I have coped for about two years in this way."

In all cases, when it was found that self-treatment had failed to remove the early symptoms and where the symptoms had either persisted, worsened or where new symptoms had developed, the patients then took the step of the communicating their illness to those within their social network, discussing their symptoms and seeking advice. At this juncture, there were two sources from which the patient could draw in seeking advice on the best course of action that he or she could take in the treatment of their complaint. Those two options were, advice from the lay person, and consultation with the medical practitioner.
LAY CONSULTATIONS

It was found that nearly all patients had discussed their symptoms with other lay persons after having communicated their illness by means of verbal or non-verbal signs to other members of their social network. Many of the patients consulted directly with their close kin to discuss their symptoms and to seek advice. Whilst the lay person in most of these cases were the spouse and/or their children, there were some close kin consultants who were other family members, such as parents, sisters and brothers. As well, for some of the patients, the consultants were found to be neighbourhood friends or social acquaintances. There were also others outside the family/friend circle who offered their diagnosis and treatment. As Mrs. Nunn, a Buddhist nun, stated:

Yorms, [laywomen who look after the worldly needs of monks] who came to the temple to make merit, told me that it would be eradicated only by taking yalouang [herbal medicine prepared by drug companies and recommend for home use by the government, not the home-made remedies as mentioned in other accounts]. . . . I didn't have to pay for the drugs, they bought it for me. About a month later, I suffered from bleeding, they said "don't worry, it's a sign of menopause", so I did nothing about it. I also felt shy and didn't dare visit the doctor. It was only after another nun told me "you must go to see the doctor, you can't just stay here and do nothing, you have already been bleeding for 5 months", that I decided to visit the doctor at Mouang Garn [a commonly used name for Kanchanaburi province], the lady doctor.

There was no explanation from most of the patients as to why they selected a particular person as their illness consultant. However, Mr. Adoul, one of the patients was able to give the following account:

Although I usually I went to see the doctor whenever I became ill, the reason that I didn't go to see him this time, was because of the fear of AIDS. . . . I thought, Damn it, as I had been with prostitutes quite often . . . then I went to see my father and asked him for some herbal medicine . . . he is a herbalist.

Mr. Adoul further related that there were only certain types of illness that influenced him into making up his mind to seek help. And so, after noticing an ulcer at the base of his tongue, he did nothing, as there was initially no pain that he could associate with the visual signs of the ulcer and it was six months before he felt slight pain at the site of the ulcer. As well, at that time there were many people talking about the horrors of the AIDS
epidemic and television footage often showed AIDS patients with chronic ulcer which then made him think that he might have contracted that disease. This idea prevented him from seeking help from his local doctor, he gave the following reason:

In the eyes of the public, AIDS is a disease which means being rejected by society as well as being incurable. At that time, I thought if I have AIDS the doctor would not be able to cure it anyway, and the fear of rejection from my society influenced my decision in not wanting to visit my doctor. So, I went to see my father [a herbalist] as he would keep my concerns a secret.

There were some patients however, who did not discuss their symptoms with anyone, and it was their families or other close confidants who noticed the visible signs of sickness, such as, bleeding from the nipple; mass at the neck; loss of weight; and loss of voice, and which prompted them to broach the subject with the patient and to discuss the situation directly with them. As Mr. Sangiem, a patient with cancer of Hypopharynx, stated:

Up until I turned 73, I was in good health. A little while after that I began to develop a hoarse voice. I couldn't chant [whilst he was in the monkhood] very loud and it was difficult to get my voice out. I found that I had to take hot Chinese tea to get going. Later, I could hardly chant my prayers. One day, I was invited to be present at a religious ceremony where I was to bestow religious rites in blessing a recently built house. The host had noticed my difficulties, and later, after I had completed the ritual, he asked me about my voice. He suggested that it would be better for me to see a doctor to find out what was wrong.

In cases where there were more than one lay consultant, there was usually no effort made to discuss the case directly with the patient at the time of first being informed or on noticing the visible symptoms. Rather, they would discuss the situation between each other and make the decision for the patients. Mr. Prasert, who as previously noted, had already used drugs purchased from a local store for what he thought to be tonsillitis, and finding that he gained some relief from the swelling and that he was in no pain, later found that:
... One day, it was a little bit bigger, and my son, who had come to visit me from his home in Bangkok, must have noticed. He didn't say anything to me at the time, but later, he went to see my brother who lives near me. About two days after that, my brother came to see me and took me to the clinic to see the doctor. I had an idea that they had been talking about me, they must have decided then that I should go to see the doctor.

Lay Referral

It was about a year ago, while I was sitting together with my daughter and my grand daughter. My grand daughter wanted to play breast feeding with my daughter. My daughter was busy however, and she told my grand daughter to play with grandma and when she pulled my top up, my daughter saw blood stains on my nipple. She asked me what was wrong, and after I pressed around my nipple I saw that there was a small amount of watery, blood stained discharge. I told her that nothing was wrong. But one day, about a month later, after I had polished my floors, I complained of being a bit sore. My daughter told me to see a doctor.

As shown in the above discourse, Mrs. Sumarng gives an example of how her daughter responded to learning of her symptom. The initial response was to show concern but not offer any advice. Later, on finding that the symptom was more severe than first thought, reacted by simply referring her mother to see the doctor.

In the early stages, most patients did not suspect that they had cancer. As well, their families or neighbours did not offer cancer as a diagnosis. Most families and friends however, would often participate by providing information and suggestions concerning the type of treatment that should be followed with some of them preferring a traditional healing option. An example of this was in the case of Mrs. Nunn, where "Yornm told me that it [leukorrhea] could only be eradicated by taking yalouang [herbal medicine prepared by drug companies and recommend for home use by the government and not the home-made remedies]."

Many other forms of advice/referral were offered by concerned relatives and friends as can be seen in the case of Mrs. Loaun, where as well as diagnosing her sickness as an ulcer at the uterus, her mother told her to avoid ahaan salaeng (food which is bad for the health and can cause sickness) such as pickled food, catfish, chicken, pork and so on. To refrain from eating chicken was stressed as being particularly important, as
"The chicken is an animal which normally uses its claws to dig in the ground for food and if we eat the chicken it could do the same to my ulcer and make it worse. So my mother told me not to eat it."

Other advisers recognised that modern medicine should be the preferred source of treatment, especially the close kin or the relatives who lived in the major cities. An example of a case in which the adviser urged the patient to seek help from modern medical sources, has been covered in the account concerning Mr. Pratin within this chapter.

A number of patients, on reaching the stage of having communicated their illness to others and having received a lay referral from those concerned, had still not decided on any course of action. Delays in taking action were common for those receiving recommendations to seek help from their doctors. This delay was associated with personal economic problems and was directly related to their own perception of the severity of their illness. By this, the sufferer thought it more important to continue with providing for their family rather than to spend money in seeking help from their doctor. However, they would finally be forced to consult with the doctor when their symptoms worsened. This was the case for Mrs. Boontoung, who at the time had experienced heavy leukorrhea and a little abdominal discomfort. She stated:

My husband told me that I should go to see the doctor but I didn't go. At that time I worried only about making enough money for my family. I thought my symptoms were not severe enough to see the doctor. If I did go to see the doctor I would have to stop work and I would lose my income for that day and I would also have to pay to visit the doctor. So, I kept working in the rice fields as a labourer up until the time that I noticed the bleeding.

There was one case however, where a relative of the patient, who although being aware that the assessment of the symptoms indicated illness, was unable to give any further advice as to what action should be taken because of the prevailing socio-economic factors. Mrs. Nuchin, the patient in this case told how:

At first, I did nothing about the leukorrhea. I continued to work hard in the rice fields near our village as well as at home doing my daily housework chores. Later, after noticing the bleeding per vagina, I spoke to my husband. His only reply was, "What can we do?, we have no money to do anything." I knew this to be true and so I decided to tolerate my condition further and do nothing. Whilst my husband was visiting our son in Bangkok to ask for help with money, I heard on a local radio talk show that there was a government sponsored early detection programme provided free of charge. This prompted
me to see my doctor and seek help through that programme. On my husband's return from Bangkok, he told me that our son could not help with the money.

There were some patients, who although not having any economic problems, still showed an initial reluctance toward visiting the doctor and employed various delaying tactics before finally submitting to the pressures of concerned relatives over the visible symptoms and the fear of serious illness and sought the help thought necessary by those advisers.

It was found that those who adopted delaying tactics, usually came from the older age group of patients. It was also found that those relatives who exerted their influence on the elderly patients, were invariably from the younger age group and were normally domiciled away from the patients' rural area home.

In certain situations, where relatives perceived the patients' symptoms as being serious, the relatives took it upon themselves to intervene and to initiate medical consultations. As Mrs. Geing, a patient with cancer of the tongue and who later developed mass at neck related

My son came up to visit me and after he saw the lump in my neck he requested that I see a doctor. I hadn't decided at that time as to what I was going to do, so I told him that there was nothing really wrong with me. As well, I had begun to take holy water for this symptom and besides, I was in no pain, I could eat rice and all other types of food and I didn't really want to see the doctor or to leave my home. I didn't want to come here either. But, my son was worried that there might be something wrong and pointed out that I had exhibited this symptom for quite a while. He then forced me to see the doctor and to obey his instructions.

There was only the one case in which the patient knew about his diagnosis from his first lay consultation. Mr. Adoul stated:

I went to see my father and asked him for some herbal medicine... he is a herbalist. He told me after he saw the ulcer at my tongue that it was cancer for sure, and then he gave me yamor [home made herbal medicine] for cancer. I took that drug until I felt great pain in my mouth, later it became unbearable, particularly when I drank alcohol. I complained of the pain to my friend at work and he suggested that I should see the doctor.
Although Mr. Adoul knew of his cancer diagnosis from an early lay consultation with his father, he did not go to seek help from his medical doctor, but rather, preferred to seek treatment from a traditional healer. For him, cancer awareness was not the trigger to seek out help from his doctor. This contrasts with the actions of other patients who would later show that the awareness of cancer was the important cue for them to seek that form of help.

PROFESSIONAL CONSULTANTS

There were only a very small number of patients who reported that they had sought help from doctors in the early stage of their illness, without consulting any lay persons. There were different reasons given by the patients as to how this situation came about. Mrs. Lumpoo told how:

... That area [external genitalia], at first it was itchy and became ulcerated, it was sheer agony but I tolerated the discomfort. However, my condition worsened, with the bleeding becoming most discomforting and the pain was unbearable. I had to force myself to overcome my shyness and disclose my secret to the doctor and allow him to examine me. I didn't tell anyone about my condition or about my going to visit doctor.

Mrs. Lumpoo gave her reason for her actions as, "fear of rejection." A past experience with TB and the attitude shown by certain relatives toward her during that illness, had so affected her, that this time she was determined that she would keep her illness a secret from her family. Mrs. Lumpoo would later recount how she eventually had to tell her family about her condition:

No one knew that I went to see the doctor. Every time I visited the doctor, I simply told them that I had been to the market. This went on for quite a while, until the doctor told me that I had cancer and that I would have to go to receive treatment in Bangkok. Then of course, I had to tell them everything.

For Mrs. Meinten, the situation was quite different. It appeared that she was confident enough in her own knowledge to make judgement that she needed medical care. As she normally took the role of consultant within her family group, she adopted the attitude of,
"I don't think that anyone [family members] can help me." As well, having the experience of her father who was dying from cancer, alert her to the fact that she should seek a medical diagnosis from her doctor, and coupled with her noticing that the leukorrhea had persisted for about a month, finally forced her into seeking help from the doctor.

SOURCE OF MEDICAL SERVICE

The health resources utilized by patients when first consulting a doctor, were either that of local private clinics or local public health resources, such as, a general hospital, community hospital, medical health centre, health centre and so on. There were differing reasons why patients used a particular health resource to find out about their health problems. Economics and reasons of convenience figured prominently among those who utilized the public health centres, whilst patients who had money, preferred to visit the local private clinics, as Mr. Sangiem stated, "They provided a quick service, there was no queuing and you were well treated." On the other hand, those patients who had only enough for daily necessities, were forced to accept the seemingly endless queues, the time consuming waiting, along with the low priority given in their treatment provided at public hospitals and centres, where only a very small fee was asked, or as in some cases, no charges were incurred through the use of social welfare cards.

The close proximity to health resources was another factor that influenced patients decisions to use those facilities, which for most patients were the hospitals nearest to their own home village or town. There were however, some patients who decided to see a doctor at far off places. An example of this was recalled by Mrs. Mai, who lived in Phetchabun (a province in the northern region), but who had reported her early symptom when consulting a doctor at a hospital in Bangkok. Mrs. Mai explained:

At that time, during the off season of rice farming at home, I had come to Bangkok to work as a labourer at a construction site. One day, my friend asked me to go with her to the hospital to keep her company, I thought why not, I would go to check a lump in my left breast at the same time. So, I went with her but the doctor said there was no evidence of cancer and that I didn't have to do anything. The doctor suggested that an operation would have been necessary if his examination had found something wrong such as a sore lump, a watery discharge from the nipple, or a bigger lump.
MEDICAL CONTACT

For most patients, the process of being referred for treatment, was not at all complicated, although they would tell of many and varying experiences encountered in contacting their doctor before that referral. After initial contact, doctors who had informed the patients, or a close relative, that they had cancer, would then refer them on to Siam Hospital. This information was given either after the doctors' first examination or after the results of the pathological examination were known and usually consisted of the diagnosis along with statements emphasising the importance of immediate treatment for their illness. It was also emphasised that the diagnosed condition would necessitate the type of treatment which was only available at the regional hospital or a Bangkok metropolis hospital. As Mrs. Nunn stated:

...I went to see the doctor at Kanchanaburi, [a province of the central region of Thailand] a lady doctor, she told me that I had cervical cancer and that I must go to Bangkok as soon as possible for further treatment. She then wrote a referral letter and told me to go to whatever hospital was convenient for me, either Siam Hospital or Pracha Hospital.

Mrs. Meinten, in the early days of her illness, had gone to see the doctor upon noticing abnormal symptoms. She related how:

...it was heavy leukorrhrea, then I went for a check-up at Nakhon Prathom [a province of the central region of Thailand and only 30 kilometres from Bangkok]. The doctor cut out a little piece of my tissue and suggested that I take the specimen to a private laboratory at Bangkok so that I would not have to wait so long for the results. Two days later, I picked up the results and after they were seen by the doctor, he said, "The pathology tests reveal that it's cancer" after which he suggested that I go to Siam Hospital for radiation treatment. He also mentioned to me, "Don't believe everything you hear, you have a chance to be cured."

As previously mentioned, some of the patients were not informed directly by the doctors of their diagnosis, but rather, became aware of their situation through a variety of informative sources. For one patient, information concerning her malaise came in the form of overheard discussions between the doctor and other members of the medical team. As well, the observed actions of others was a clue to her in her effort to determine the extent of her illness. As Mrs. Utorn claimed:
My doctor didn’t tell me. He might have told my husband. ... I know, because I heard the doctor talking to the others whilst he was examining me. He used awful words. It scared me. ... later, I had no doubt after my husband told me of the forthcoming treatment and the plans concerning my going to the treatment centre the day after the examination.

This statement was later confirmed by Mrs. Utorn’s husband, who on visiting her during a treatment period at Siam Hospital, related how:

I knew from the beginning, from the very first time that we went to see the doctor at Phetchabun [a province of the northern region]. He said, "It’s probably cancer." The doctor didn’t tell Utorn. He told me not to tell her and that she must go to Bangkok for further investigation. He also told me to prepare myself, to accept it as it is a most serious disease. ... I told Utorn much the same thing, to prepare herself and to accept it as it is a most serious disease and could not be cured at the hospital in Phetchabun. My words must have made her suspicious, as she cried and said that, "It must be cancer."

For some patients however, the process of referral for further treatment was more complicated, especially with those patients who went to see the doctor at the health resource centres where only meagre facilities were available to perform a cancer diagnosis. The diagnostic investigation procedures therefore, took longer and were more complex than in the cases of those patients previously outlined. As some would find out, that although they had made initial contact with the doctors at the various health resource centres, there was no guarantee that they would undergo the simple pathological test that would help determine their diagnosis. It was the usual practice for doctors to only inform the patients of their condition in terms of, "Things are not good" or "It is probably benign" before referring them to a larger hospital.

As recalled by most patients, the reasons given by the doctors for their referral on to a larger hospital were usually, "for further investigation" or "for further treatment." Patients who asked to be treated or tested at their local hospitals were told by their doctors, "The hospital here has no facilities to do anything for you. You must go to the hospital that I have suggested."

Although there were no diagnoses given at the time, the mere act of being informed by their doctors that further investigation or further treatment was required, was a strong enough message to bring an awareness to the patients that their condition was serious. As well, it was usually successful in influencing their decision into following the doctors suggestions and report to the referred hospital.
For the convenience of the patient, the hospitals to which they were referred, were either the regional or general hospital closest to where the patient normally resided. At those hospitals, patients were again examined, with most of them undergoing some form of pathological test, after which they were then told to return home and wait.

After waiting at home from between ten days to one month, the patients would receive a letter from the hospital's administrative department. As Mrs. Chuan explained:

... After the doctor had cut some tissue from me for further examination, he told me to rest at home and said it would take about ten days for the results to come back from Bangkok. ... Later, I received a letter informing me that the results were waiting for me at the hospital. I then reported to the provincial hospital where the doctor told me that I had cancer and that I have had it for the last five years. He also told me that I would have to go to Bangkok for treatment, because there was no facility at that hospital.

It can be concluded here, that regardless of whether patients were informed of their diagnosis by the doctor on initial contact or as it was for some, only after being referred on to another hospital, most patients or close relatives were to learn of the diagnosis before being referred to Siam Hospital for advanced treatment. Also, most patients told how the doctors did not inform them of what type of treatment they could expect at the treating hospital, although most patients were assured by their doctor that they had a good chance of being cured.

There was yet another group of patients who encountered an entirely different set of experiences when consulting a doctor. These patients found, to their chagrin, that they were unlucky enough to see an inexperienced doctor who could not detect their cancer or mis-diagnosed their symptoms completely. In these cases, many of them openly blamed the doctors for causing a delay in their seeking treatment for their disease.

In cases where patients or their close kin were not convinced of the diagnosis, or that not enough was being done to find an explanation for their illness, it was the patients themselves or family members who made the important decision of intervening in the cancer diagnosis process. That is, on reporting their abnormal symptoms, patients were met with rather indifferent attitudes displayed by their local doctors who in some cases did not take them seriously. Examples of this were given by patients who had been told by their doctors that, "It's not a serious condition" or "Don't worry, the tests have proved benign." This, of course, only strengthened the patients' and kin disbelief as they felt that those statements were untrue, or at best, misleading.
Later, as the patients accounts unfolded, they would show that the attitude of some doctors was further questioned by them as well as their families in their concern over the form of treatment prescribed. This was the case for Mr. Prasert, a cancer of the tonsil patient, who after adhering to the wishes of the doctor for over a month, found that his son, in making further assessment of the obviously unimproved condition and sensing that all was not as well as the doctor had suggested, took action by making him change doctors. As Mr. Prasert put it:

... My son wasn't happy with the inattentive manner of the doctor and thought that he should be doing more than prescribing vitamin tablets. So, he took me to see another doctor at the provincial hospital in Rachaburi (a province in the central region of Thailand). My new doctor, Dr. Piradaj sprayed medicine into my throat and cut out little pieces of tissue. He asked me to go back to see him after one week to hear the result. When I went back to see him he didn't give me any medicine, he just sat down and wrote the letter referring me to this hospital. He then told me that I would have to undergo radiation treatment, although he did not tell me of the diagnosis. I think that was because he did not want to upset me. I didn't bother to ask him about it as I already knew that I had cancer. I knew, right from the time he did not tell me of my examination result.

Some of the patients, in feeling that their condition was more serious than that indicated by the doctor and expecting more treatment than what was being prescribed, continued to press the doctor for further investigation into their illness, as well as for a more intensive treatment regimen. Mrs. Mai, a breast cancer patient related:

I went to see Dr. Vichea as soon as I felt the sore lump in my breast. He examined me and after pressing on the lump said that it wasn't cancer. I went back to see him six or seven times and he only gave me an injection. ... He said that the lump was smaller, but I felt that it was the same as before. I tried to keep calm and tried to trust his judgement, although I had mixed feelings of belief and doubt in what he was telling me. There was no one whom I knew that exhibited the same symptoms as I. Later, I changed doctors and requested that he remove my breast as I was in great fear of cancer. My new doctor referred me to a surgeon, who after lightly touching my breast told me that he would have to take some tissue from the affected area to help in determining what should be done. Again, I asked the surgeon to remove my breast. ... I had no thoughts of regret in wanting my breast removed. ... The surgeon ignored my request, and after waiting for one month, he informed me that the test had proved that I did indeed have a cancerous growth in my breast, and that I would have to have it surgically removed followed up by a course of radiotherapy treatment. He asked me to go to Bangkok for the operation, but I told him that I wanted to have the surgery done at the provincial hospital and that I would go to Bangkok for the radiotherapy later. I was afraid that it would be too late if the operation was delayed any further.
In the case of Mrs. Sumarng, another breast cancer patient, things were a little different and the questions that she directed at her doctor were not on the prescribed treatment, but rather, about her concerns over the diagnosis of her condition. After again examining her breasts, the doctor told her that the signs supported his original diagnosis and that it was benign, but strangely enough, he did suggest the removal of the nipple.

At that time, Mrs. Sumarng put off having an operation at the request of her sister who had seen one of the villagers suffering from a rotting breast after a breast operation. As well, she thought that if it was not cancer, she would not risk an operation. However, Mrs. Sumarng's daughter felt worried over whether or not the doctor had given the correct diagnosis and told her that she had heard of a place called The National Cancer Institute in Bangkok, where she could go for a check up as part of a cancer detection programme and according to Mrs. Sumarng, "She really tried to talk me into going for a check up, if only for her own peace of mind."

Later, a doctor at the institute, after conducting a physical and X-ray examination of her breasts, informed her that the results were negative and that she was free from cancer. Not long after her return home, she decided to have an operation because she was becoming annoyed with the blood oozing from her right nipple and staining her clothing as well as the ever present fear of having cancer. However, after the operation she felt a small lump in her right breast near the operation site and on informing the doctor, she was told that it was normal and not to worry. By this time, she was rather desperate and began to take herbal medicine which she obtained from a herbalist not far from her home. After more than a month of this form of self-treatment, she noticed that the lump was bigger and so returned to the hospital once again where she consulted another doctor as she felt that her own doctor was not paying the required attention to her symptoms.

An examination by the new doctor confirmed that her condition required the removal of her breast and she was referred back to her own doctor to perform the operation. It was just prior to the operation that her own doctor finally told her that her right breast would have to be removed, as it was cancerous and that she would have to have follow-up radiation treatment in Bangkok afterwards. Although the operation went quite smoothly, the wound would later became infected, forcing her to wait for another two months before it had healed sufficiently to allow her travel to Siam Hospital for radiation therapy.

Generally, at this stage of the health-seeking process, where patients had made contact with a medical doctor and had undergone some sort of medical examination and whether or not they fully understood the whole meaning of their illness, all patients knew or
suspected that they had cancer. Becoming aware however, was not a straightforward event and it was seen that for patients under study, initial awareness was derived from a variety of sources, the most important of which were the medical doctors, from whom the majority of sufferers would receive the news through direct statements, whilst for others, awareness would come in more roundabout ways, such as, the overheard comments of their doctor in discussions with others, prompting from close kin, or from their own personal curiosity and suspicions.

Treatment Actions

In Thai society, the individual's beliefs about cancer illness influence his or her ideas about the treatment. Within these perceptions, lay an abundance of ways and means on how to deal with the disease, and which would usually include the type of treatment that should be administered as well as the appropriate source used in providing that treatment. Because most patients pictured cancer as "a severe illness"; or "it has shortened my life"; and "without treatment it would become rotten and smelly" as well as to cause "dying in agony"; and so on, these ideas of cancer would necessarily force them into taking things seriously and do anything and everything possible to find a cure for their illness.

It was found that after becoming aware of their illness, patients were quick to forget about their existing economic worries and domestic problems and began to take things seriously in seeking help for their illness. In some cases, patients went as far as selling their property or even to borrow money to pay for the expenses incurred in seeking the necessary treatment. As well, instead of only offering suggestions, their families and others in their social network, now showed more concern and helped the patient in various ways, with some giving monetary support whilst others offered the services of their labour to maintain the patients' business and to give the patients an opportunity to seek the necessary treatment.

Becoming aware of their cancer disease was a major turning point for patients in seeking an answer to their illness and saw patients react in markedly different ways. All patients did mention however, that is was their awareness of a cancer diagnosis that was the important influencing factor that kept them within the modern medical care system and to continue to seek help from medical practitioners. One patient remarked, "I think cancer has to be treated by the modern doctor" whilst another stated, "I don't think that herbal medicine can cure cancer. It can't compete with modern scientific technology."
The decision to seek treatment from within the medical system was seen by most patients as being an appropriate health-seeking medium. It was however, not until after the patients became aware that radiation therapy was the prescribed treatment, that many would turn to the use of herbal medicine as an alternative treatment.

In contrast, there was only one patient who would mention that cancer awareness was the cue for him to choose an alternative treatment from the outset. This became evident in the case of Mr. Adoul, who had received a cancer diagnosis from his father, a herbalist from Suparnburi (a provincial city of Thailand's central region). Although he would have normally visited his doctor in times of sickness, being a government official and having easy access to a wide range of government medical facilities, he decided to use the medicines supplied by his father, believing that cancer could be cured through the use of herbal medicine. He told of events that supported his belief:

I have seen my father treat many cancer patients and cure them of that disease by using herbal medicine. I saw one patient came to see my father with a large rotting ulcer at his leg, my father told him that it was cancer and gave him herbal potions to put on the ulcer. It was not long before the ulcer was being eaten away by that drug and could be peeled off in strips. My father would not give that drug to me because it was dangerous. It contained cyanide and was only used on the exterior parts of the body. He gave me another drug but it did not work for me. Really, if I had cancer on the outside of my body and not at my tongue it would be cured by now and I would not have had to see the doctor.

As previously mentioned, it was the awareness of cancer that was the important influencing factor which kept most of the patients at seeking help from within the medical system. Also, most patients had elected to follow the doctors' recommendations of leaving their family and home to travel to the hospital in Bangkok (Siam Hospital) for treatment. At that time, most patients had some knowledge about alternative forms of treatment such as herbal medicine and curative magic and the claims of them curing cancer, and although they remained ambivalent in their attitudes toward those treatments, most patients preferred to try the modern medical approach in a search of a cure. Although most patients also held negative views toward radiotherapy being the recommended form of treatment, they would nevertheless, make the decision to select radiotherapy as the preferred treatment medium in a bid to cure their cancer. The reasons given for this decision were many and varied and differed from patient to patient and are illustrated in the following patient accounts:
Mrs. Von:

At Phetchabun hospital the doctor said it was cancer and told me to come here for radiation therapy. . . . Someone said radiation therapy would shorten my life. . . . I didn't believe that. I wanted to be cured. I didn't listen to them. . . . I didn't know of any other way to cure my disease either. I thought, if I did nothing I was going to die from cancer anyway. So, I'd better try.

Mrs. Meinten:

I knew that cancer is an illness which is difficult to cure. My doctor told me to come here for radiation treatment and told me not to believe everything that I heard. Before I came here someone said that radiation would cook the flesh of my body. At first I couldn't sleep, but later, when my husband told me about one of his friends who had the same illness as I and that after radiation therapy she was still alive, I felt better. Someone suggested herbal medicine to me but I think cancer has to be treated with modern medicines. Herbal medicine can not compete with the modern medicines available today.

Mrs. Kesorn:

My friend who brought me here, told me not to be afraid of the radiation therapy. She knew some of the staff at Siam Hospital and had accompanied 2 or 3 other patients to this hospital in the past and they had returned home having being cured. Someone back in my home town suggested to me that I should take herbal medicine. However, I decided not to take it and I came here instead. As well, I *krong jai* [in this context, a wish to comply with the wishes of] my friend who brought me here. She is so good to me and cares so much about me.

From these accounts, it is shown that the reasons under which the patients surrendered to treatment were, the appraisal that their uncertainty was a danger, presenting itself as a treatment opportunity; trust in doctors' knowledge and their ability in curing cancer; trust in the therapeutic effect of the treatment; as well as, out of respect for the wishes of a close friend.

Not all patients remained within the medical care system, with many of them deciding to drop out in an attempt to find alternative treatment for their illness before finally returning to the medical care system. The important questions of, *When did these patients drop out?* *Why did they drop out?* *What did they do about their cancer illness during that time?* *Why did they decide to came back into the medical care system?*, were among those put forward in the hope that the answers coming from the patients would help lead to an understanding of the actions and experiences of those cancer patients which has previously been labelled by the provider, as non-compliance.
It was found, that within this group, patients dropped out from the medical care system at no one particular stage, although most patients did tend to defect soon after having being informed that they would be receiving radiotherapy as part of a treatment course. As well, some had made the decision to drop out soon after receiving their diagnosis and even before the intended treatments had been prescribed. As Mrs. Chuan recalled:

... the province doctor only told me to go to Bangkok for further treatment. But someone said, for those who have this disease the treatment must be radiation therapy. I was afraid. ... the one who lived in my village, the one with cancer and who had received this form of treatment before, said that the disease wouldn't be cured if I was to receive radiation therapy because it would cause the tissue to harden and become resistant to any other form of treatment. At that time, I really was afraid and decided not to follow the doctor's advice to come to Bangkok, instead, I took herbal medicine following a suggestion from an advertisement on a local radio station. I took that medicine for about two weeks, 4 pots of it. Then my daughter asked me to go to Bangkok for more appropriate treatment. She said that I was not going to be cured by taking herbal medicine as I had already taken many pots and I still had severe bleeding. I believed my daughter then, so I came here for treatment.

In the case of Mrs. Chaun, her decision to use herbal medicine was influenced by her past personal experiences relating to a conversation she once had with a cancer sufferer over the forms of treatment that could be expected. As well, the lack of information provided by her doctor concerning medical intervention, limited the enhancement of her knowledge into formulating a trust of medical science.

Although patients took some form of action in choosing either conventional treatment or an alternative treatment, there were some patients who preferred to combine treatments in the hope that the overall therapeutic effect would in some way, help to cure their illness. However, in the case of Mr. Pratin, a cancer of the esophagus patient, experimenting with herbal medicines as an interim measure whilst awaiting radiation treatment, was done with the intention of foregoing that treatment if the alternative medicines showed signs of being effective. He related how:

... I heard someone talking about the effect of herbal medicine, so I decided to try it whilst I was waiting for my radiation treatment to begin. I thought it might work or at least stop the progression of the disease while I was waiting the treatment. I took yamor [home made herbal medicine] for about two weeks and only stopped the day before my appointment, then I came down here for treatment.
Some patients, although having reported to Siam Hospital on a number occasions without receiving any medical prescription or any notification of what the intended treatment would entail, decided not to proceed once it was known that radiotherapy would be the treatment medium and returned home, electing to take herbal medicine as an alternative means of treatment. An example of this was seen in the case Mrs. Utorn who told of her early trips to Siam Hospital soon after her doctor's request to do so:

My husband accompanied me here on my first visit and after undergoing tests I was asked to return home and come back at a later date. I did this a number of times without receiving any kind of medication or news concerning my illness or what my treatment would be. I still had no thoughts of turning away from the medical system whilst in the process of planning for my treatment. But when I was informed by the doctor at Siam Hospital that radiotherapy would be the recommended form of treatment, I didn't say a word to the doctor, but simply walked out of the hospital and went back home where I asked my husband to buy yamor to cure my cancer.

In the case of Mrs. Utorn, her initial decision not to accept the radiation treatment was influenced by her friend and her mother. To help in the understanding of this process, Mrs. Utorn's husband explained:

I had to go to buy herbal medicine for her. She believed in what the neighbours told her about how herbal medicine could cure. But, she couldn't take it because its smell would make her feel sick and cause her to vomit. She must have been allergic to it. I spent about 700-800 baht for that stuff which she couldn't use. At first, she refused to have radiotherapy because her mother told her that someone in the village had died after receiving that kind of treatment. Her mother told her not to have radiotherapy if the doctor suggested it, but to ask for alternative treatment.

Mrs. Utorn later returned to see a doctor at Siam Hospital, being forced by her husband and her father to come down and accept the radiation treatment as suggested by the doctor. Her husband went on to say:

She is very stubborn and insisted on not having radiotherapy right up to the time of her visit to this hospital [Siam Hospital]. The doctor called Utorn, her father and I into his room in an effort to get her to make a decision. Later, after a long talk, she gave her consent, although it was given in an unwilling manner. She cried again after that.
Mrs. Tongpreow, another patient who had decided to take herbal medicine as an alternative treatment after radiation treatment was offered, told of how she arrived at her decision. She recalled:

... The doctors asked me to rest at home after the investigation and made the appointment for the radiation therapy. ... My fear of that treatment was heightened by my neighbour when she told me that radiation would cause the illness to become incurable as well as causing a fever, my hair to fall out and many more effects. I was afraid, so I decided not to come. ... there was also someone who said that the radiation treatment fee was very expensive, that it would cost about 4000 - 5000 baht. Oh!, what could I do? I had no money, I didn't dare come, I felt ashamed of having no money. ... At first I decided on no treatment and thought that if I had to die, let it be. But, my sister's mother-in-law suggested that there was a famous herbalist who was able to cure this disease. He lived at Samut Prakarn [a province in the central region], so I went to see him. I took the herbal medicine, about 15 pots in all. Whilst I was taking the medicine I suffered none of the symptoms that I had experienced earlier. I had no abdominal pain although a watery discharge was still present and I managed to gain weight. I don't know why. I later decided to come here because I heard someone say that at the present time the doctors here are very good and that the radiotherapy treatment could stop the illness and would dry out the watery discharge. As well, the treatment here was free of charge if you had no money.

Mrs. Bootoung was another example of where a sufferer, after being diagnoses as having cancer and already booked in for treatment at Siam Hospital, would turn to an alternative source due to her fear of suffering whilst undergoing radiation therapy. She told her story:

I didn't turn up for my radiation therapy treatment. Many people in my village told me, "Don't go to have radiation, it's not good." My mother also. She didn't want me to come here to have radiation. So, I decided to seek a cure from a traditional healer in the village of Ban-kram, [a village of] Lopburi [a province in the central region], not far from ours. He began by giving me yamor to take, as well as giving me the foot treatment in order to draw the toxins from my body. He applied oil, which he had made specifically for that kind of treatment, to his foot then stepped onto the very hot coals of a fire he had prepared nearby and then massage my abdominal area with his foot. I spent 2 months and 10 days there, then I went home because my bleeding had stopped. I thought I was cured. But, after only one month I began bleeding again, and so, I went back to see him again. This time he asked for 5000 baht as a treatment fee. I told him I had no money and that I had already paid him 3000 baht for the previous treatment session which he had promised would be returned if I was not cured. As it was, I had to borrow that 3000 baht and this time he was asking for 5000 baht.
I had no money. I was very angry, and eventually the talking turned to quarreling. In the end, he blamed me as the cause of my relapse, that it was all my fault. He said it was because I slept with my husband. I told him to let me swear to die in the face of the sun if I had slept with my husband. I had not slept with him for more than a year. He did not reply to that, but resorted to lowering his fee to 500 baht. I told him I had no money, not 500 baht, not even 300 baht. It was no use, so I went back home and took herbal medicine. But, this only stopped the bleeding for a while. During Buddhist Lent, I entered the nunhood and vowed that I would get better. It was on about the third night of my stay at the temple that I had massive bleeding with abdominal pain. I felt like I wanted to go to toilet, but when I went all I did was lose a lot of blood. I felt weak and had no energy to walk and had to be helped to the toilet by my sister and my mother. The trips to the toilet became more frequent and I later lapsed into unconsciousness. When I awoke, I was in the district hospital. I felt a lot better after the doctor gave me intravenous fluid and blood transfusions and he asked me whether I would go for radiation treatment. I told him I wouldn't go, I wanted to die at home which was better than suffering and being in agony from radiation therapy. He convinced me to go, but I told him I wanted to try herbal medicine. At home, I went to buy herbal medicine, and at every place I went to they said it was good. Eventually I was taking two different herbal preparations together, both were Chinese herbal medicines. I took these for about a month and I was beginning to feel better, but it was to only last for about a month after which I had another bout of massive bleeding. This time, my mother told me to come here for treatment, saying that there was no other way left to treat it as I had already tried everything, radiation was my only remaining chance. So, I came here.

Some patients, having initially overcome their fear of the treatment and its debilitating side effects, decided to continue on within the treatment programme. It was only after they had observed and spoken with other patients who were undergoing treatment and were experiencing those effects that they decided to quit, opt out and return home. As Mrs. Nunn related:

...The doctor had marked the lines for treatment and asked me to come back the following day to commence the treatment. I went back to my relatives house, packed my bag and returned to the temple where I lived. Whilst I was in the hospital, I saw patients left alone and who were obviously in great pain during their course of treatment. It looked awful. People in my village had told me that radiation treatment was not good, that it would cook the flesh on my body and would cause suffering and that none of the medicines would work because body tissue had been destroyed. On returning to the temple, I began to take herbal medicine which I obtained from many sources, some from famous monks, some from friends or relatives. It initially worked and gave me some relief and there was less bleeding. I continued with that medicine for about nine months or so, but the symptoms still persisted. During that time I went to various hospitals to have checks done again and all the doctors referred me to Bangkok for radiation therapy treatment with no promise of a cure. I was feeling very sorry for myself and after the last bout of bleeding I went to see the doctor at a local clinic and he told me that I had many ulcers at my cervix. I hadn't heard anything further from the other
doctors, so I went out and bought about twenty sleeping tablets. I took them that night hoping to kill myself, but it didn’t work. I then decided to come to this hospital again because there was nothing else left to do. I couldn’t do much else. I had no other way to go.

Some patients however, although having reported to the treatment centre and who were actually undergoing treatment, changed their minds and decided to ‘drop out’ and not continue the treatment programme. One of these patients, Mrs. Mann, recalled:

... On appointment day I was told that the radiation machine had broken down. The doctor then injected me with a colourful medicine and after only seven days I lost all my hair. ... When the next appointment time came around, I didn’t report in. My sister told me not to come down for any further radiation therapy and suggested that I take herbal medicine. I followed her advice and began to take that medicine, then after about eight months, I had massive bleeding. My son took me to the province hospital where I told the doctor the truth about taking herbal medicine instead of undergoing radiation treatment. The doctor tried to convince me to return to the treatment centre and undergo radiotherapy and encouraged me in saying that there was still hope. At that time, I still believed in herbal medicine and I had never received radiation treatment before. I told the doctor that a woman had told me that she had seen radiation patients who died a few months after returning home from the treatment centre, and that those patients who had died, had become very weak and lethargic due to cell death. Although the doctor explained to me that those patients had most likely died because the disease had gone too far, I didn’t believe him and went back to taking herbal medicine again. About one month later, I began to suffer from massive bleeding, three times in all, which forced me to seek help again from the local hospital after each bout. During my last visit, the doctor told me that he couldn’t help me any more, that the cancer had gone to the blood vessels and that if I had another bleeding attack and couldn’t get to the hospital in time, I would die. He urged me to return to the treatment centre and wrote a letter to the hospital in Bangkok, but I didn’t go back. Instead, I went home and rested and after only one day I had another bleeding attack, so I came to this hospital.

As indicated in the above accounts, patients’ decisions to turn away from the medical care system were made at differing times throughout the health-seeking process, being mainly, prior to treatment being prescribed; soon after a doctor’s treatment suggestion; just prior to commencing a treatment programme; and even whilst being an active recipient within a treatment programme. A common factor behind patients decisions to turn away from the medical system and attempt an alternative treatment medium, was their fear of radiation therapy treatment. The degree of threat from radiation treatment alone was enough to sway patients into deciding to accept other more traditional means of treatment.
Moreover, this factor was magnified when combined with economic hardship which saw patients who were considering the odds of gambling their entire savings or life resources in an attempt at survival, as not being a worthwhile investment. As well, the fear of radiation treatment harboured by family and friends of the patient and the subsequent dissemination of those fears to them, was also an important factor that influenced their decision to turn away from treatment. Thus, fear and economic status were the dominant factors which influenced patients' decisions either not to proceed with or to withdraw from radiation treatment.

The type of treatment that most patients turned to as an alternative medium was the use of herbal medicines which in some cases were combined with other treatment such as magic ritual behaviour with the administration of each remedy depending on consultations held with their traditional healing advocates. Although most patients in this category experienced a persistence of their symptoms, the greater number did not turn away from the use of herbal medicine in the first instance. Instead, they simply changed healers, going from one to another until finally, after trying a number of the various remedies available and showing no improvement, returned to the medical care system for radiation therapy.

Patients' decisions of turning back to radiation therapy were influenced by the evaluation of the non-improvement of their condition as well as the expressed concerns of their close kin towards the ineffectiveness of traditional therapeutic alternatives. The concerns of medical doctors however, carried no weight in influencing these decisions.

Summary

It can been seen from patients' accounts that the natural histories of cancer illness in Thai cancer patients were complex and rich in their social and cultural meaning. In evaluating the aspects involving patients' health-seeking process, it was found that their cancer awareness and the type of treatment received, especially that of radiotherapy, were influential in changing patients' behaviour in seeking a way of solving their problem. That is, cancer awareness turned patients from the more traditional treatments to that of modern medical treatment. In contrast, the awareness of radiation treatment as prescribed by a medical doctor was the major factor which caused many patients to turn to a traditional treatment.
The accounts from Cancer Hostel patients showed that their responses to medical advice and recommendations were varied. There were some patients who showed their respect of their doctor’s knowledge and followed through with the advice given until they entered Cancer Hostel. However, there were other patients who turned away from any form of modern medical treatment and sought alternative treatment from the various sources available to them before finally turning back and accepting the advice given by medical practitioners.

It was found that knowing or suspecting a cancer diagnosis as well as being aware of the severity of the symptoms were significant factors in influencing adherence. As well, family members often took on an assisting or controlling role in influencing patients to adhere to medical advice. It was found in some cases, that when patients and/or relatives became aware of the cancer diagnosis, the patients low economic status was no longer an important factor in decreasing adherence. Rather, they tried everything they could to make adherence possible.

It was clear that the fear of a radiation treatment regimen was the most significant factor that interfered with the consistency in which patients adhered to the medical recommendations. These non-compliant patients then sought alternative treatments which were later found to be less than satisfactory, thus forcing them to turn back to a medical system that many patients expressed as being their last hope.

From the presented experiences of these patients in their efforts at health-seeking, it was found that none had reported that their awareness of a cancer diagnosis was a factor that forced them away from modern medicine, but rather, it was a significant cue for them to stay on with the modern treatment means. Instead, it was the fear of the proposed treatment, especially that of radiotherapy which caused them to turn away from modern medical means and to try the various forms of alternative treatment available.
CHAPTER 6

THE SHELTER

Introduction

In this study, the initial focus was on the ways in which patients who were residing in Cancer Hostel coped with their life situations. This meant collecting information about the world which most immediately affected the patients' illness and treatment, their fellow patients, the institution's staff, as well as the patients' relatives and friends.

During the time of this study, patients were referred to Cancer Hostel by one of the four cancer treatment institutions located in Bangkok and which were within reasonable travelling distance of Cancer Hostel. Although informed by Miss Yarchai (the hostel's housekeeper), that there were 70 beds available, I was later to find (through my unobtrusive investigation) that there were normally only between 44 and 61 beds occupied at any one time.

Siam Hostel was the largest treating centre and referred the greater number of patients to Cancer Hostel. The number being referred at the time of this study however, had recently been reduced. Dr. Rut, a senior staff member of the Radiological Department of Siam Hospital and the secretary of the Cancer Society, would explain:

The number of patients coming from Siam Hospital are fewer because some of the treatment equipment has broken down from over-use which has reduced the number of patients being treated, and of course, the number being referred to Cancer Hostel. However, with the new equipment which is expected to be installed shortly, the number of referrals will again increase.

Even with this reduction, the number of patients from Siam Hospital was still higher than the other institutions, whereby, during the last six months prior to the commencement of this study, 133 patients had been referred from Siam Hospital, whilst a combined total of 162 were referred from the other three institutions. The number of referred patients being treated on a daily basis at the time of this study ranged from 14 to 21.
Early in this study, it was intended that the daily life events of all Cancer Hostel patients would be followed. This idea was later modified as it would entail commuting between Cancer Hostel and the four cancer treatment institutions as well as monitoring the non-treatment hours of all patients residing at Cancer Hostel. For this and other reasons, I concluded that I could ill afford the time spent in all that travelling and decided to follow only those patients who were referred by Siam Hospital. This decision presented me with two distinct advantages, in that the majority of patients residing at Cancer Hostel were referred from Siam Hospital, as well as being within close proximity of that hospital’s treatment centre. As well, I had the added advantage of being one of the nursing staff of Siam Hospital and was at that time on study leave which made it easier for me to ask permission to conduct the research and to gain entrance into the desired field setting.

Over the five months data gathering period, there were approximately 111 referrals from Siam Hospital to Cancer Hostel and of those, 21 patients were selected and their life situations followed intensively throughout their stay at Cancer Hostel. As well, the pre-admission histories of those selected patients were thoroughly investigated. For the duration of my stay in the field, additional information would also be gleaned from patients who were returning for follow up treatment at Siam Hospital, whereby, selected patients were interviewed over those life events which occurred after leaving Cancer Hostel.

Though it was intended to follow all cases from referral to discharge, one patient remained undergoing treatment when I finally retired from the field. This patient had suffered from the side effects of the combined treatment of chemotherapy and radiotherapy and had at one time, been removed from all treatment and allowed to recover before being put back into the treatment programme.

The History

Construction of the Cancer Society office and its 30 bed hostel was completed in 1968. It was the first and remains the only shelter for cancer patients in Thailand. The society, which is now under the patronage of His Majesty The King, was founded in 1962 by Professor Dr. Anun and his wife Mrs. Thip. Dr. Anun, then head of the Radiological Department at Siam Hospital, found that the increasing numbers of patients and the problems of overcrowding within the hospital system, forced him to look for alternative accommodation for his patients.
After discussing the problems with his wife, a volunteer social worker, they decided to establish a cancer society and invited the participation of doctors, nurses, housewives and social workers in forming a committee which would attempt to address those problems.

In the early years, this committee had the responsibility of looking for free accommodation for patients, who for a variety of reasons could not find or pay for accommodation close to the treatment centre. This was achieved by placing them in non-hospital facilities, including local temples as well as the recuperating house of the women's cultural club.

Difficulties arose later in the efforts to keep patients in those institutions as other non-cancer patients could not tolerate the accompanying bad odour of most of those afflicted with cancer. This, along with the fact that there was no permanent office building from which the society could base its operations, would force the committee to consider other ways by which it could provide for its charges.

The society therefore, became involved with an increasing amount of fund raising activities. Land was donated in a suburban area and monitory grants were received from the government as well as the public sector which enabled construction to begin on the first building of the society's new home.

His Majesty, King Bhumiphon Adunyadej (Rama 9) presided over the opening ceremony of the buildings which included religious and government participation. The King of Thailand, in line with his policy of being an active participant in the affairs of his subjects, presented certificates of appreciation to those who had donated money to the society.

After the original L shaped building was completed, the society received funds donated by an American millionaire couple which would allow the setting up of an anti-cancer foundation. With interest on invested funds from the foundation, along with public donations, the society continued to grow and in 1968 after purchasing a small block of land adjoining the original site, a second building of 20 beds was completed. A third and final building was added in 1976, being built onto the second building and constructed as a mirror image with no sign that they were constructed separately, they thus formed the one I shaped building.
The Present

The complex as it was seen at the beginning of the research study, consisted of a cluster of dull, cream walled buildings standing within a crowded suburban residential area, a one and a half metre high concrete fence being the only barrier from the rows of three storied shophouses that squeezed in against it.

At the entrance were the signs for, "The Cancer Society", as well as the "Anti Cancer Foundation" which included a sign to encourage donations from the public. There was also a sign showing the hours of operation for the "Cancer Clinic" for the early detection of cancer. There was however, no sign to indicate that a Cancer Hostel was indeed part of the complex although it was well known by that term rather than what was shown on the signs.

As pointed out by the taxi driver on dropping me off at the entrance on my first visit, "Next time, it would be easier if you ask for Cancer Hostel rather than the Cancer Society." Similarly, in the latter days of my stay, when dining at a small restaurant nearby, the owner asked, "Are you a cancer patient? I saw you walk out from the Cancer Hostel."

During my first visit to the society, an overcast July afternoon, my first impression on stepping from the taxi and glancing quickly around as I walked through the entrance, was one of optimism. Large, lush green trees and beautiful tropical palms were at the centre of a grass strip which bordered a rather wide concrete driveway as well as flanking the extremities of the entrance grounds. This had the effect of invoking a sense of welcome whilst affording protection from the noise of the bustling outside world.

Within the grounds were the normal car parking facilities, neatly trimmed lawns with a balance of shade trees providing a pleasant atmosphere for all those who enter. As well, there were two important structures, one the bust of the late founder of the society, the other a small spirit house (a shrine, which is usually in the form of a miniature temple mounted on a raised pedestal and is a place of prayer and the paying of respect to the spirit of the past keepers of the land). Both structures are the focus of reverence, prayer and respect and without doubt, more important in meaning than the society's buildings themselves.
The spirit house which stood in a cool shaded area just inside the entrance, is part of Thai traditional culture and is linked with the land on which the buildings and grounds are situated. It was draped with colourful garlands whilst aromatic smells from burning joss sticks and incense hung heavily in the surrounding air. Neither by intent nor impulse, but rather, as an automatic response to encountering the spirit house, I stopped and paid respects to the spirits, asking permission to enter the grounds and to begin the work of recording the daily life of the patients housed within.

A short distance along the drive, a red ceramic tiled pathway sloped up into the adjoining L shaped, three storied main building. This sloping pathway was laid over an existing older pathway which was however, usually under water after heavy rain.

The problem of inadequate drainage had been severely felt for the previous five years and was a legacy of major reconstruction work done on the road and main drainage system in front of Cancer Hostel. The result of this 'engineering feat' had left the level of the street and public drainage system slightly higher than the area on which the society stands. As one can imagine, even the daily waste water from the complex could not drain adequately, thus leaving a large amount of water in the pipes as well as spilling out through broken sections and open inspection ports. The smell from the trapped water was a continual source of patient and staff complaints.

During the rainy season, which came on whilst I was at the society and after particularly heavy rain over a period of four days, most pathways were under water. The patients, staff and all those who visited, had to use the submerged walkways when moving between the buildings and from the complex to the outside world. The housekeeper, Miss Yarchai, commented:

The drainage system is very poor. It was like this before I started working here, I have reported it to the committee many times, but to no avail. Nothing has been done except that one walkway has been raised, but we still get our feet wet after heavy rain and the water backs up.

The committee had in fact attempted to do something, but in being quoted a price to rectify the problem found that it could not afford to have the whole job done, but did have the pathway raised. From the point of view of project priorities, it was my belief that the committee had this one particular pathway fixed, not only for the benefit of visitors to the society but more so for their own convenience.
With the sun already behind the neighbouring buildings and an overcast sky further reducing the natural available light, the entrance to the main building was gloomy and uninviting, the light from the low wattage ceiling lamps were of little help. The initial feeling of welcome and optimism suddenly began to drain away, leaving a feeling of foreboding and apprehension.

On entering, and allowing time to adjust to the gloom, I quickly became aware of the sparse fixtures of the hallway, a public telephone booth attached to the wall, a wooden desk with two seats and some old fashioned wooden lecture room chairs lining the other wall immediately below an honour board listing the benefactors of the Cancer Society.

At the far end of the entrance hallway I was confronted with a life size wall chart of a human skeleton along with 'the six winning posters' from an anti cancer campaign held five years previously. This display, although well meaning in nature, gave me the feeling that death lurked close at hand and further added to the feeling of gloom.

It was in fact, the proud work of Miss Yarchai the housekeeper, who with good intention, had arranged the display as a reminder to all for the need to be on guard against those things in life that aim to rob us of our good health. She later stated, "I placed the display in that part of the hallway in order to educate the visitors to this society of the horrors of cancer and to frighten them into seeing that bad habits equal cancer and cancer equals death."

The effect it had on those who were confronted with such a display was not quite as envisaged. To be sure, the display had the effect of frightening those who saw it, but as the majority of those who would pass this way were patients already admitted to Cancer Hostel and undergoing some sort of treatment or were part of the early detection programme, it was for them, an area to be avoided as much as possible.

Along the wide entrance hall, a number of doors allowed entry to the various facilities. To the right, a large conference room which was used for committee meetings, religious ceremonies, the occasional lecture on cancer or related topics and at times as a reception room for the larger groups of visitors.
At one end of the conference room was a small stage decorated with the Thai national flag, an image of the Buddha and a portrait of His Majesty The King (This follows normal Thai protocol whereby the three important cornerstones of Thai society listed here in order of precedence, were accorded the necessary respect). Chairs and tables were stacked at the opposite end of this room being placed out for use only when required.

Across the hallway was the examination room used by doctors when conducting the clinic for the early detection of cancer. This clinic was far from busy during the period of the research study with only four to five members of the public visiting the clinic on the Thursday afternoon of each week. As well, the staff lavatory was located in one corner of this room.

Entry to the Cancer Society office was also from the main entrance hall and was furnished with a cane lounge suite placed at one end of the room in front of a full length glass and mirrored wall. The opposite wall had windows which overlooked the staff quarters and work area. Four desks, each with two chairs were centrally located with only one showing signs of having been worked at. Built-in cupboards lined two walls to waist level being separated in one corner by a large metal cabinet which was used for securing household medicines and washing agents and even the office telephone in non-working hours. A refrigerator containing only water stood just inside the door.

Although the office was the centre for all activities conducted by the society, the housekeeper was normally the only staff member in attendance, whilst members of the committee came to the office only when there was a meeting or when a particular activity concerned them as an individual. From her desk, the housekeeper could look through the glass wall and observe all those entering and leaving through the main entrance area. As well, the work area of the kitchen staff could be seen quite clearly without Miss Yarchai having to move from her desk.

Directly opposite the main entrance was a stairwell leading up to an open hall on the second floor. This hall was large and unfurnished with only a large picture of Professor Anun and Mrs. Thip in formal Thai dress on one wall and a round clock fixed to another. The windows were bare of curtains and with the exception of the afore mentioned fixtures, no attempt had been made to make this area appealing or to utilize the space to the benefit and comfort of those patients staying at Cancer Hostel.
Patients' rooms were on both sides of the hall with the females room closest to the stairwell. Both were large, open and well lit from the numerous windows which allowed natural light to enter for most of the day. With the exception of the 15 beds lined up in regimental fashion and the small bedside cabinet beside each, there was no other article of furniture provided for the patients' personal comfort.

Two ceiling fans which were a constant source of complaint and as pointed out by one of the female patients, one was inoperable and the other noisy and in poor working order and interfered with the patients sleep at night as well as their day rest periods. Patients had tried various ways to overcome this problem, firstly, by moving their beds away from the noisy fan and when that didn't work, by turning it off, with the latter being the least effective, as Mrs. Utorn remarked, "Last night I could not sleep because of the noisy fan, so I decided to turn it off. However, it was then too hot to sleep and the mosquitoes began to bite me all over, so I had to put up with a noisy fan all night."

There was no public room provided for the patients and with the exception of a black and white TV located at one end of the females room, entertainment and relaxation facilities were non-existent. The old TV on its metal stand faced down the aisle formed by the two rows of beds. There were no chairs provided and the female patients would sit on the floor between the beds whilst the male patients preferred to sit up on the empty beds. Because of these inconveniences as well as fear of disturbing others, most of the patients declined to watch the TV except when a popular programme such as Thai drama, Thai boxing or international soccer was shown.

Lack of toilet facilities were also a major concern to the patients and although there were two toilets and two bathrooms at the end of each room, only one toilet in the males room was able to be used. In this case, all patients on this floor had to share this facility with many of them feeling uncomfortable and frustrated.

Mr. Sangiem, a 73 year old male patient with hypopharyngeal cancer, complained:

It is dreadful, I have to perform my ablutions in the toilet cubicle and before I can begin I have to empty the small built-in concrete water container and fill it again to ensure that the water is clean. Really, I can't stand using the water in that container when I know that someone has used the toilet and may have fouled the water whilst washing their private parts.
Some male patients had suffered emotionally and complained of the lack of privacy when female patients walked through their room. Moreover, a few of the older men felt that their "purity" had been taken away by sharing the toilet with the female patients. To cope with this situation, some patients used the public toilets at the hospital during their weekday treatment visits and opted to return home at the weekends rather than put up with what were to them, intolerable conditions, longer than need be.

Some male patients showed no concern in the matter and accepted the existing situation. Mr. Adoul expressed his feeling, "I don't mind, what else do we want, the toilet is very clean, the staff are good and they clean it for us, patients are always making it dirty. I really don't mind to share the toilet."

Female patients also had problems with the communal nature of the toilet facilities. Mrs. Von, a cervical cancer patient told how:

At night, I only go to the toilet only when I cannot hold it any longer. I never go alone, I just wait until someone else from my room also wants to go, or if it becomes urgent, I ask another patient to accompany me. I really don't like to bother the other patients, but sometimes the urge to go is unbearable.

During the daylight hours, Mrs. Von was willing to walk downstairs to use the toilets available in the other building, stating "I would rather do that than be seen by the male patients when visiting the toilet in their room."

The problem of inadequate toilet facilities seemed to affect the female patients more acutely as most of them were embarrassed at having to walk through the male patients room. Mrs. Wanna, one of the female patients said:

Although I have already been here for two weeks, I still become embarrassed when I see the men looking at me when I walk past them on the way to the toilet. It is even worse when I see the men laying down or walking about in their underwear. I feel as if I am 'running the gauntlet' every time I make the trip.

Although Mrs. Wanna knew this was only because of the heat and was not meant as an offence against her femininity, she could not stop the feeling of embarrassment at the loss of self modesty.
Going downstairs to the other toilets or suppressing the urge to go was not easy for patients who suffered from complications, such as diarrhoea, after receiving radiotherapy. Mrs. Wanna stated:

It was terrifying, it was an emergency and someone was in there, I couldn't hold it any longer so I knocked on the door asking to be allowed in. I felt the urge to go many times and was in and out all night. I realize that this can cause an angry reaction from some patients, but most understood and tendered their sympathy toward me.

Although the housekeeper was quite aware of the existing problems, having brought them to my attention during my first visit, it was quite obvious after subsequent conversations that she was unaware of the resulting discomfort suffered by the patients. Equally obvious was the fact that she held the patients directly responsible for the drainage and sewage problems. Miss Yarchai told of her theory:

When I started working here, all of the patients toilets and bathrooms in this building and some in the other had to be closed because of the severe blocking of the system. All this has come about because of the patients habit of disposing of sanitary napkins by flushing them down the toilet and allowing plastic bags to be washed down the open drain holes. I had the system repaired by replacing the blocked pipes with those of a larger diameter and by having the western style pedestals in all patients toilets removed and substituted them with the Asian type which has a smaller opening.

According to Miss Yarchai:

This proved successful for a while after which the same problems reoccurred, forcing the closure of most of the toilets. I have attempted to educate the patients in the correct ways of disposing of those items but as you can see, the problem still exists. The patients continue to discard them into the sewage and drainage systems.

It was noticed however, that there were no receptacles provided in any of the patients' facilities for the safe disposal of the offending items.
The third floor of the main building was unoccupied and contained only a few items of furniture which obviously had not been used for quite a while. Up until five years prior to commencing this study, this floor was used as private accommodation by the two previous housekeepers as well as the meeting place for society members.

The current housekeeper decided not to use this accommodation area from the beginning of her employment, stating, "It's only a five minute walk from my house to here. As well, the water pump is broken, making the supply of water to this floor most unreliable." A few weeks later however, on talking to a number of staff members from Siam Hospital, a different story emerged as to why the third floor was not in use. It appears that the first housekeeper was found dead in her room and there has been a number of incidents since that time that would suggest that all was not right on the third floor.

The official cause of death was having died of heart failure, but those who state that they are privy to the real reason, hint that she was "poisoned by persons unknown." There have also been a number of unexplained feelings of a presence in that area as well as dreams experienced by members of the staff that appear to be associated with the event and the departed housekeeper's room. On my part, there was no further investigation of either reason.

The second, or L shaped building was located to the rear of the complex, running parallel to and connected with the shorter wing of the L shaped main building by a sheltered driveway that is now used only by pedestrian traffic. Four benches lined this walk, a group of two near the second building and the remaining two closer to the main building. Patients and staff often came to this area to sit and rest or talk amongst themselves.

Later, during the course of an interview conducted in this area, a patient hesitantly informed me that patients were only allowed to sit on the two benches closest to the L shaped building, the other two being reserved for staff members. To comply with this 'in house rule' when conducting interviews in this area, I made sure that the right benches were used.

Large stone steps with concrete benches lining both sides led to the entrance hall of the second building. This area was a focal point for interaction within the patient groups, being at the junction of the pathways leading to the dining room and laundry area as well as to the main entrance. Patients frequently gathered here to sit and relax after a meal or after washing their clothes or to wait for the transportation which would take them to the hospital treatment centre.
The entrance hall, like most of the ground floor areas throughout this building was also dark and gloomy as the main building kept it in shadow for most of the day. The high fences at the rear were built on top of and as an extension to the original society fence by the neighbouring shophouse owners, making it quite clear to me that this was an effort by them to cut off all contact with what they must have assumed to be an unsavoury environment. As well, the old fashioned, wooden lecture room chairs lining one wall and a broken clock on the opposite wall did little to lift my spirits as I tried to take in the atmosphere of the establishment at the centre of my intended study.

As is customary in all Thai institutions of this nature, as it is within a normal home environment, an area just inside the door was set aside for relatives and other visitors to remove their shoes before entering any of the patients rooms. It therefore came as a surprise to me, during one of my early visits to the patients rooms, to be told by the housekeeper, "Oh, it’s not necessary for you to remove your shoes, I have never taken mine off when entering these rooms." Needless to say, to remain as a viable and reputable researcher among a people having the same upbringing, ideals and social behaviour, I removed my shoes and placed them alongside those of the patients before entering their living area.

This building consisted of two female patients rooms and one staff room on the first floor with one male patients room, one female patients room and two staff rooms on the second floor. Screened doors on both sides of the entrance hall opened into the patients' rooms which were, with one exception, laid out in similar fashion.

Five beds on either side were inter-spaced with small bedside cabinets which allowed the storage of only a few personal possessions. Two ceiling fans were located centrally at both ends of the room. Fly-screened windows without curtains allowed ample sunlight into the second floor rooms whilst the amount of light to the lower floor was considerably reduced by the high wall at the rear of the complex and by the main building to the front.

Normally, when the beds were not occupied, the bright pink kapok mattresses were rolled up around the pillow and rubber sheet and set at the head of the bed. When patients were admitted they were given one white cotton sheet and pillow case with a light cotton blanket. The new arrivals were told that the bed linen would be changed on becoming soiled, but much to the patients discomfort, this was rarely done. As well, having been told to place the soiled linen under their beds they would invariably have to retrieve those items on returning from their daily treatment sessions for use again that night. The patients quickly learnt that they were the ones that had to wash their bed linen.
Some patients were initially not supplied with clean linen having to use that already on the bed and which had been used by the previous occupant. Others, either because they had arrived late in the afternoon or because of the inadequacies within the hostels administrative system, would have to spend the night without linen, having to cope with this inconvenience as best they could.

One morning, when visiting the patients before they left on their daily trip to the treatment centre and seeing some of the newer patients using the mattresses without linen, I made enquiries with a number of them. Mrs. Chuan, who had arrived the previous day, mentioned:

I was not given any linen yesterday when I arrived, so last night I slept on top of the rubber sheet with my bath towel covering the pillow which is dirty and smelly. I did not have a good nights sleep and I feel a little tired now. I hope that I can get some sheets and a pillow slip later today.

When asked why she did not ask for some linen when she first arrived, Mrs. Chuan replied, "I'm new here and I don't know who to ask, maybe they will give me some today, maybe they didn't have any to give me yesterday." The items mentioned were supplied to Mrs. Chuan later that day after returning from the treatment centre.

It was during these early morning conversations, at times when some of the patients were making up their beds, that I was to learn that they had been encouraged by the staff to put the rubber sheet over the linen to keep it from becoming soiled. This of course, did not make for a comfortable nights sleep especially when it is remembered, that in Bangkok, the night temperatures rarely get below 26 degrees Celsius and with only the two fans to give any hint of relief, things could become rather unpleasant. As could be expected, many of the patients preferred to sleep on the floor, thus overcoming the problems of an uncomfortable nights sleep and that of soiling the linen.

Although each room had two bathrooms and two toilets, the problem with the sewage and drainage systems permitted only half of these facilities to be used. Even with these restrictions, problems were still encountered as any overflow from the second floor seeped through the concrete and tiled floors and dripped into one of the rooms below. This one room did not follow the standard layout, as the beds were arranged to avoid the water that would often drip from the ceiling. A half forty four gallon drum, which at one time had contained bitumen, was positioned to catch the dripping water.
Of the two very small staff rooms on the second floor, which were originally meant as rest areas for single members, one was being used as accommodation for married staff members as well as their families. As it would later turn out, after being informed of Mrs. Thip's (the founder’s wife and president of the Cancer Society) decision to allow me to stay in Cancer hostel, I was assigned to quarter in the remaining unoccupied staff room. I was later invited by the housekeeper to inspect the room that would be provided, and where I would have to work and sleep among the stored, personal items of one of staff members.

On being introduced to my proposed living quarter, and after quickly taking in its dimensions and contents, it was not difficult for me to conclude that the small room was not overly appointed with creature comforts. Measuring 3.5 metres long and 2.5 metres in width, a door with a broken lock, three fly-screened windows and the available clear floor space covered with a vinyl mat, greeted my more than inquisitive gaze. Stored equipment took up the remaining two thirds of the total floor area.

Noticing the worried look on the face of the staff member when asked by the housekeeper to remove those items, and not wanting to intrude into the staff domestic arrangements, I mentioned to her, "You don’t have to remove it all, just rearrange it a little bit and leave enough room for me to sleep. That will be fine." The only thing that was requested of the housekeeper, was for the lock on the door to be replaced to allow the door to be secured from the inside at times when I would sleep at Cancer Hostel.

This request was granted immediately and on being accompanied by one of the domestic workers to a local shop to purchase a suitable lock, I was informed that, "This place is very safe." Later however, after having withdrawn from the field and whilst paying a visit to the the staff, I was told that one of their members had her personal belongings stolen while she was away on holidays.

When I moved into Cancer Hostel, about one week after inspecting the room, it was clean and some of the stored items had been removed with the remaining items being stacked neatly at one end of the room, thus providing enough space for me to place one single bed sheet on the floor and sleep on that. A coffee table, which was to become my work station, a clothes horse and an electric fan had been placed in the room, compliments of one of the staff, to be used for the duration of my stay in the Cancer Hostel setting.
A single toilet facility, built into the space under the first floor staircase, was to be shared with two staff members as well as the family of one of those members. The cramped, insecure and communal nature of this facility made bathing and toilet activities most trying.

Cleanliness and tidiness were of major concern to the staff and patients with the staff encouraging this aspect of daily life by placing signs at strategic positions throughout the buildings such as on the wall behind the TV and on the bathroom and toilet doors. These signs read, "Please help each other to keep this area clean"; "Please tidy your bed area before going to the hospital"; and "Don't throw your litter on the floor." As well, the patients were at times given impromptu lectures on the subject by the housekeeper, for which the patients would sit or stand in silence and listen attentively to what was being said.

As well intentioned as these lectures may have been, they were at times, for some of the patients, harsh and unrealistic, especially when being lectured on the banning of the consumption or the storage of food in the patients rooms. This was especially so when considering that some of them, as a result of their condition could not eat in the dining hall or at the specified times and would bring their meal or uneaten portion back to their bed area. As well, no provisions were made for hostel cooked meals to be eaten outside of the three established meal times or for the patients to have an area set aside for the storage of 'special' food brought in by the patients or their relatives and friends.

Despite the reminder signs and the occasional lecture, it was common to see the patients carrying out cleaning tasks that should normally be done by staff members. This was done on a voluntary basis as an additional cleaning routine carried out by the patients to satisfy their own stringent values of cleanliness, even though it may have previously been done by staff as part of the normal daily work schedule.

The odour which accompanies many types of cancer was of great concern to the patients who were thus stricken, as it was for those who lived with them and used the same facilities. Patients would employ various means to rid themselves and their surroundings of those odours with some patients washing their clothes whilst others placed them outside to 'air in the sunlight', even if that clothing had been worn for only a few hours. As well, there was a continual flushing of the toilet, either before or after use of that facility.

On some occasions however, these efforts were not very effective as in the case of Mrs. Mann, who suffered from cervical cancer which had advanced to a stage where there was a
foul smelling discharge which was particularly noticeable when she used the toilet. Although she flushed the toilet many times in her efforts to rid the area of the bad smell, Mrs. Mann was well aware that the smell would still be there to offend other patients. Later, when talking with me about her embarrassing moments, she revealed, "I know that there is still a smell in the toilet after I use it, but I clean the area thoroughly and flush it many times. What else can I do?" Mrs. Mann was also aware that other patients would talk about her predicament and hold her responsible for fouling that area.

The patients rooms were not provided with rubbish receptacles, but rather, the patients were asked to place their rubbish in plastic bags and to discard them into the large bins at the rubbish collection point located to the rear of the I shaped building.

Close to the rubbish collection point was an area set aside for the patients to wash their clothes and bed linen. This area was constantly wet from the water that backed up from the broken drainage system which prevented water from the washing point and the kitchen from draining away quickly. The fetid smell of stagnant waste water was quite noticeable when visiting the lower floor of the building and one was constantly reminded of the water problems, as the slightest breeze from that area would bring those smells wafting through the patients rooms on that level.

At one end of the concrete and gardened area which separated the two main buildings, stood a double storied wooden structure containing the dining area, kitchen and cook's accommodation, and although joined at the roof level, they were not connected by any means that would allow thoroughfare between either adjoining buildings. A tree lined, concrete pathway led from the entrance of the I shaped building to the dining area with its adjoining kitchen built along its full length, providing some privacy and protection for the dining area which was open on its other three sides.

Five long wooden tables with accompanying wooden benches were set out to the left of the dining area, beyond which was a large metal tank which collected rain water runoff from the roof. A stainless steel sink with the bottom half eaten away by rust, was provided for the patients to wash their eating utensils, needless to say, the only way for them to clean those items was to wash them under the running water. Fixed to the wall above the sink, was a water filter which could provide only a trickle of rusty water and
according to the cook, "The filter was broken a long time ago. A new one is desperately needed as the patients are currently having to buy their drinking water." An unservicable washing machine set centrally against the wall of the kitchen, was to me, yet another symbolic gesture in providing one more, non-existent facility.

The opposite end of the dining area contained a row of four old lecture room seats facing a single wooden table with chairs set to either side. Although not signed to show it, this area was set aside for the private use of the cook and her family, who at times, would sharply rebuke the unsuspecting newcomer and advise them that, "The area to the right of the old lecture room chairs is out of bounds." Likewise, the kitchen was also the cook's private domain with a sign prominently displayed on one door, which read, "Clean Area - Patients Not Allowed." The upper floor of this building was taken up with private accommodation for the cook and her family.

The Staff

There were four permanent staff members employed by the Cancer Society to provide for the general needs of those patients referred to stay at Cancer Hostel and who were undergoing treatment at either of the four treatment centres in the Bangkok area. The staff employed at the time of this study included, the housekeeper; one cook; and two domestic workers. None of these staff members had any medical or nursing oriented background or training prior to employment.

HOUSEKEEPER

Miss Yarchai had graduated from year twelve high school and had worked as the housekeeper at Cancer Hostel for the past five years. Prior to this appointment she had worked part-time for one of the private organisations which used the meeting room of the Cancer Society for their regular meetings. On the resignation of the previous housekeeper, the position was declared vacant as no nurse had applied or expressed any interest in applying for that position. Dr. Rut, the secretary of the Society, told of the reasons behind the appointment of the present housekeeper:

We knew Miss Yarchai was not a trained nurse, but we had to employ her because there was no other nurse interested in this position. Maybe the money we offered as salary was not enough to attract a nurse into this job. We don't have much money to allot in the form of wages for this position really. The two former housekeepers were retired nurses, but it seems that no one, not even nurses who have retired, are interested in this kind of position any more.
Miss Yarchai accepted the full-time housekeeper job that was offered to her by the president of the society who had known her from her previous job. She knew that she was not qualified for her position and had gained her present knowledge from reading medical books and from the doctor on duty at the early detection clinic who had spent time in teaching her the general nursing tasks involved in preparing the patient for examination. At the time of this study, she was also enrolled as a part-time student in a health care education course of a Teaching University and was expecting to graduate in two years hence.

As housekeeper, Miss Yarchai had overall administrative responsibility for the patients, the other Cancer Hostel staff, as well as the facilities of the Cancer Society. She said of these responsibilities:

I am not a nurse, the best thing I can do is to make sure that the patients have a place to stay. I can't help the patients in times of severe illness. If the patients' problems are not severe I can help them with the administration of normal non-prescription drugs which are provided free by Siam Hospital. If their symptoms are severe, they are sent to Siam Hospital for immediate treatment, but as most patients are able to provide self-care, we encounter very few cases where this actually happens.

It was noticed that a division existed between the housekeeper and the patients under her charge. This observation was reinforced when Miss Yarchai mentioned that she found many patients had difficulty in answering her questions when she conversed with them. As well, she believed that the patients actually liked to make the linen and the floors in their rooms dirty, and told how in order to solve the problem, she had to enforce the rules of, "Patients are to keep their pillow cases and sheets clean" and "Patients are not allowed to have their meals in their rooms." She found however, that quite often, many patients did not respect the rules and in spilling or dropping their food, caused the floors and linen to become soiled. As well, in order to enforce those rules, she had to, "keep an eye on the patients at all times." From the observations made during my time spent 'living in' at Cancer Hostel, it was found that although some of the patients did consume part or all of their meals in their rooms, they were always careful not to soil any of the facilities and would make meticulous efforts in cleaning up as soon as the meal was over.

In relating her story about the patients' habits, Miss Yarchai mentioned that she had also found that there were some patients who gossiped about the contents and preparation of the meals, on which she made the point:
There is not much that I can do about that as there are limited funds available and because the cook has to prepare simple food which everyone can eat. As well, the patients come from different parts of the country with different food preferences, so it is hard to please everyone's taste.

In working with cancer patients, Miss Yarchai found that "loneliness" was the most commonly expressed feeling of those staying in Cancer Hostel and that most of them would at one time or another during their stay, suffer in some way from this feeling. She believed that most of the doctors in telling their patients that they had cancer, would also inform them that the "bad tissue" was not harmful to them. As well, she thought that most of the patients already knew that they had cancer from the snippets of information volunteered by their doctor during previous encounters. She also thought that the patients showed an implicit trust in their doctor, in that, "they believe whatever the doctors say."

The housekeeper did not live on the premises, a point she thought unimportant in mentioning that, "My house is only five minutes walk from here", but other staff members thought the reason was because "Khun [a respectful title used for persons of either gender] Yarchai feared the ghost of Khun Jun [a former house keeper]." Working hours for Miss Yarchai were from 8.30 am to 5.00 pm on working days, as well as on those special occasion weekends when she was required to be in attendance. Because she lived off the premises, her responsibilities outside those times then fell to the staff who lived in. On this point, of placing herself away from the sphere of her work responsibilities, she said, "If they want me, they know where to find me."

The relationship between Miss Yarchai and the patients can best be described as very loose and could be directly attributed to the very little contact that existed between them. This lack of contact became quite evident and is best illustrated by the fact that most of the patients did not know who she was. The entry procedure, as well as the daily routine at Cancer Hostel meant that the patients and the housekeepers paths rarely crossed.

When the patients first arrived, they were greeted by one of the domestic staff who had been assigned by Miss Yarchai to carry out the task of admitting them into Cancer Hostel. By neglecting that simple but important task of being present on first contact, she further eroded the position of a care provider and did little to foster a relationship between herself and those under her charge.
The housekeeper's working hours saw that she commenced her work after the patients had already departed for the various treatment centres and finish her work about two hours after their return, a time when the patients were usually exhausted and would rest in their rooms until called for the evening meal. For me, this was another opportune time lost for the housekeeper to become more familiar with her charges.

The only times that Miss Yarchai made contact with the patients were when she thought it was necessary to act on the complaints of the domestic staff that the patients had in some way, broken the rule of keeping the place clean and tidy at all times. She would normally broach the subject with them when they were gathered in the dining hall for evening meal or as observed on one occasion, in the patients' rooms prior to evening meal. She would scold them in a domineering albeit inoffensive manner and remind them of the "golden rules." After one such 'lecture', whilst I was was sitting and conversing with the patients and after Miss Yarchai had left the room, one of the patients who had been in Cancer Hostel for about three weeks, asked, "Who is that woman?"

Although contact between Miss Yarchai and the patients was minimal, she continued to dominate the lives of her charges by maintaining control over them through the actions of her staff. As well, during the times that Miss Yarchai did make direct contact with the patients, it was felt by them that her attitude was one of 'looking down' at them and communicating in a stern, domineering manner. As Mrs. Meinten mentioned, "The manner in which she speaks to us here, the way she tries to educate us, is one of castigation."

Whilst this account of the housekeeper's daily work schedule is not meant as a critical exposé of the administrative mismanagement of Cancer Hostel, it is thought that it is warranted to bring out these points to illustrate the effect it had on the patients. It did appear to me, that Miss Yarchai, by the way in which she approached her duties in the daily running of Cancer Hostel, was directly responsible for the conditions that existed in that institution at the time of this study.

It was felt that Miss Yarchai exhibited insecure behavioural patterns in the way she approached the job of running the day to day activities of this important institution. As well, her problem solving techniques and her habit of explaining away the deficiencies in the administrative running of the hostel so as not to be left with the blame, did little to reassure that she could in fact, be in full control in the event of any crisis.
In assigning members of the staff to positions of responsibility in the daily administration of Cancer Hostel, and by her failure to monitor any of the allotted tasks, Miss Yarchai lost whatever control she may have had over the way in which those tasks were carried out. The lack of supervision demonstrated by Miss Yarchai and her method of control by proxy, also meant that she knew nothing of the problems that existed within the institution and which more than likely, were created by the staff themselves by the way in which they dealt with the day to day concerns of the patients. These problems were encountered by the patients on a regular basis and although they came to my notice, they eluded that of Miss Yarchai.

COOK

Mrs. Tuk was the longest serving member of the staff, having worked at Cancer Hostel for more than ten years. She had been hired to fill the position of cook without having any previous experience in that field except what would be encountered in normal home cooking. Mrs. Tuk lived on the premises with her family. Her husband was an ex-policeman who had been expelled from the police force because of corruption allegations two years prior to the commencement of this study. Mrs. Tuk had two sons, the eldest being ten years old from her first marriage, whilst the youngest at five year old was from her present marriage.

Mrs. Tuk was a big woman, talkative and spoke with a loud voice, quick to show her bad temper and was often drunk in her off duty evening hours. Her drinking habits would sometimes affect her job, with her husband having to work as the cook for her at times when she was hung-over. Patients told me that on one occasion, they were called for breakfast at 4.00 am. They recalled that the cook had told them that she had set the wrong time on her alarm clock, but all patients and other staff members believed the gossip that she had been drinking the night before and was afraid to sleep for fear of not being able to wake at the right time. So she had decided to cook and serve the meal early before going to sleep.

Mrs. Tuk was aware that the meals she prepared were not good enough. In defending her position, she put the blame onto the president of the society, complaining that the amount of money given for food was not enough. She related how:

Khun Thip [the president of the Cancer Society] gives me 1500 baht per week for the meals, this amount has not changed for more than ten years. I have often asked for that amount to be increased as the the cost of everything has
gone up. But there has been no answer. I have no choice. You know how much one kilo of pork costs at the moment. If I go to shop at the market nearby, I'm certain that I would run out of money. But I allow time and and a little of the money to travel to shop at the cheaper market near Siam Hospital, so that I can manage the amount of available funds spent on food.

However, about one month before leaving the field, I was told that the meal money had been increased to 2000 baht. There was no explanation as to why, but this increase came about after the housekeeper received a telephone call from Dr. Rut who had enquired about the meals after being told by the patients that they couldn't eat it. Mrs. Tuk was described by the housekeeper as being:

... difficult to govern. Sometimes I have ordered her to do something for me, but if she was not in the mood, she wouldn't do it. As well, she often brawls with her husband, I have warned her many times, but she still continues with that sort of behaviour.

When asked about her feelings toward the patients, Mrs. Tuk replied:

I pity them. Sometime I support them by talking to them. Some people object to being near cancer patients because of the smell and their appearance, but I don't. I used to help the patients, even the one who had an awful ulcer on his neck and no one would want to go near him.

There was some evidence however, that suggested that Mrs. Tuk's behaviour to be just the opposite. This was particularly so when observing Mrs. Tuk at her kitchen duties during meal times when she came into contact with the patients.

On one such occasion, early in my stay, Mrs. Tuk did not notice that I had joined the patients in queueing for their evening meal. Some of the patients at the head of the queue had asked for khaosom (wet-cooked rice) after being served khaosuay (dry-cooked rice) without being asked their preference. Without any provocation, the cook began to yell at the patients, abusing them for no reason other than some of them had asked for a different type of rice. On then noticing that I was queueing with the patients, she momentarily showed that she was caught off guard and quickly changed her manner to that of being nice to the patients.
Mrs. Tuk objected to the patients coming too close to the kitchen area and had a sign erected on the kitchen door which read, "Clean Area - Patients Not Allowed." Also, from the information that was passed around by word of mouth, the patients knew that they were not to walk into her family's dining area. Although Mrs. Tuk did not give any reason as to why the patients had limited access to the dining hall facilities, most of the patients sensed that she harboured an unsympathetic attitude toward them. Mrs. Kesorn assumed, "She must object to us going near her, we must be repulsive to her. If she didn't object to us going near her, she would not have put up that sign." Mrs. Wanna also felt this rejection and remarked, "She [the cook] must really object to us being here and is afraid of catching the disease. Even her children are not allowed to come near us."

Many patients noted that the way which Mrs. Tuk spoke and acted whilst I was in her presence was not the same as when she had only the patients around her. A number of patients made mention that they were glad when they saw me at the dining table because I acted as a safeguard for them from the abuse of the staff.

Meal times then, were not an enjoyable experience for most of the patients, with many of them sharing feelings of anger and hurt over the way in which they were treated at those times. Later, when expressing their feelings to me on the way in which the earlier event had effected them, patients made their point by telling how, "I felt hurt and wanted to cry" or "I couldn't eat any more although I was hungry" or "I ate quickly and hurried back to my room to get away from her."

However, it was seen that Mrs. Tuk would talk to the patients more often than other staff members, sometimes in the patients' rooms, sometimes on the benches located along the pathway between the main buildings. The patients later disclosed, that Mrs. Tuk wanted to sell tickets in an illegal lottery. Mrs. Samran said, "Mrs. Tuk will speak to us in a very nice way when she wants us to buy tickets in the lottery."

DOMESTICS

Miss Kai, a twenty-two year old single woman who tended to be a little over weight, was one of the two domestics who were employed by the society to do the household tasks within the Cancer Society under the direction of the housekeeper. On finishing year ten schooling, Mrs. Tuk (The cook) who was her relative, recommended her employment to
the president of the society when one of domestic positions became vacant. She got the job and had worked in her position for the last five years. Although she appeared happy in her work, she wanted to change her job because of the low pay and the absence of any retirement benefits. As well, she had a fear of contracting cancer from the patients.

Miss Kai had also been allocated the task of greeting the new patients and assigning them to their bed areas. During the initial period of contact with the patients, Miss Kai would stress the concerns she had on cleanliness and that it should be uppermost in their minds during their stay at Cancer Hostel. Because of the authoritative stance taken by Miss Kai in giving this message at such an early stage after their entry into Cancer Hostel, most patients thought her to be the housekeeper.

It was evident during my stay at Cancer Hostel, that Miss Kai had become the subject of much patient gossip with many patients mentioning that she was not really a friendly person and was quite often rude to them. On one occasion, the female patients made their feelings known when they gathered around me and told how Miss Kai had been rude to them. They related how Miss Kai wanted to find out who it was who had made a mess in disposing of their food scraps. One of the patients recalled Miss Kai saying, "The scraps have made a terrible mess around the area near the bin" and that Miss Kai had walked amongst them whilst they were having their dinner, stopping to ask a number of patients directly if they knew who had done it. After no one had owned up to the deed, Miss Kai really showed her anger and shouted, "If there is no one here who will make this their responsibility, I will." She then yelled, "I want everyone here to pick the bones up from the floor with your mouths."

It was obvious that Miss Kai's actions had not pleased the patients who must have decided to enlist a friendly ear as their only means of making a protest. In the capacity of participant observer and knowing the way of the Thai, I did not intend to take the contents of their complaint past the walls of Cancer Hostel, except in the written notes contained in my researcher's field journal.

The second domestic, Mrs. Noi, had once worked at Siam Hospital as a temporary domestic, but had resigned from that job after obtaining a permanent position at Cancer Hostel about five year previous. She did not really like working at the Cancer Hostel, a point which became clear when she once spoke with me, and where she mentioned,
"It's quite comfortable working here really, it's not hard work and I can have my family with me without having to pay rent or for use of the facilities. However, I do fear that my family will contract cancer." On being asked, "Why do you feel that way?" she replied, "I don't know really, I suppose it's because I have seen many patients with cancer, maybe it's contagious."

During her non-working hours, Mrs. Noi would spend a lot of her time with her young son and in the late afternoon she kept watch over him as he played with the other children in the grounds of the society. At about 5.30 pm she would call her son into her small room where she would bathe him, and after preparing and partaking of the evening meal, settle down to watch TV. Mrs. Noi would have normally used the room which I was occupying, but was now required to use her bedroom for all those activities. On most working days, Mrs. Noi did not have meals with her husband as he would often have a drink with his friends after finishing work, and arrive home late. Mrs. Noi would get very angry with her husband over his drinking and nocturnal habits, and the resulting fracas would often lead to a domestic brawl. These arguments would give cause for the patients to complain to me, but in all honesty I had heard none of the late night commotions which would suggest that they were saved for the weekends and times when I was absent.

In dealing with the patients, Mrs. Noi was normally very quiet and she would go about her daily tasks with little or no contact between herself and the patients. As well, when working in the patients living areas she would always wear gloves and a cotton surgical mask with her hair tucked under a plastic shower cap. The action of Mrs. Noi wearing 'protective' items of apparel were not noticed by the patients as her work in those areas was done at times when patients were undergoing treatment. For this reason, the patients did not catch on to her attitude of rejection and made only passing comments that, "That mare barn [Housekeeper, a term that covers all domestic workers] is very quiet, we only hear her when she quarrels and yells at her husband for arriving home late or for coming home drunk."

PATIENTS

From the viewpoint of those patients who crossed from normal daily life as it was, into an institutional life as encountered at Cancer Hostel, there was a general and often expressed feeling of, "at least we have shelter." It was to be a temporary home for periods of up to six weeks, a home where patients were crowded into quarters along
with those with a similar illness and treatment regimen, but who, as would soon become evident, exhibited somewhat dissimilar interests toward most other things. Despite those differences, they banded together to construct a society, which in some ways, would resemble their own home environment.

Patients who were selected to stay at Cancer Hostel were adjudged as being within a criteria of having no family, friends or other social agents, who were able to provide shelter whilst they were receiving treatment at one of the four Bangkok treatment centres. This did not mean that they had been rejected by their friends and relatives within their social arena, but rather, for reasons associated with distance, transportation or economic hardship, were unable to provide the type of support that could be found at Cancer Hostel.

A look at the similar conditions which existed for patients who entered Cancer Hostel, showed that many had no relatives or friends who they could call on to provide shelter for them, whilst some patients although having shelter, either their own home or with relatives or friends, decided to accept the offer of being allowed to stay at Cancer Hostel for a number of other more personal reasons. These would include the feeling that their dependence on relatives or friends to provide transport to and from the treatment centre on a daily basis, as being too intrusive and an abuse of the goodwill shown by those persons. As well, the patients who were given the chance to stay in shelter provided by others, considered the 'home owners' feelings in having them stay for an extended period in what was in most cases, no more than a one room dwelling, and precluded their acceptance of the hospitality extended to them.

Commuting on a daily basis from either their own home or that of a relative to the treatment centre was an expensive exercise as would be found by some patients who initially stayed in outside accommodation and it was not long before they requested and received lodgings at Cancer Hostel.

As well, monetary considerations and the tiredness from the effects of radiotherapy would present daily travel from outside accommodation as an unbearable alternative to that of staying in Cancer Hostel, with its close proximity to the treatment centre and the transportation facilities thus provided. It was also found, that as a consequence of being unable to ignore their role of looking after their own family, as well as being embroiled in the normal domestic chaos, patients who sheltered in their own home were unable to obtain sufficient rest within the home environment and had accepted the chance to shelter as Cancer Hostel.
During the six month period of this study, 269 patients were admitted to Cancer Hostel, 176 of them were female and 93 of them were male. From records kept at the hostel it was found that the cervix, breasts and oral cavity were the most frequently affected organs in females, whereas in males, cancer of the head and neck, and oral cavity were the most commonly diagnosed ailments.

Further examination of those records, found that most patients who were selected as participants, were married and had children. In terms of education, it was found that only one patient had graduated from a technical school, whilst the majority had completed a mere four years schooling, with a number of patients having received no education whatsoever. With the exception of ex-government officials who were entitled to receive limited medical support, the older patients, having reached the age of retirement, had no listed occupation or means of support, whilst other patients had been forced to abandon their jobs because of the stigma associated with a cancer diagnosis. Many patients had an occupational background as farmers or farm labourers, with some having a current interest in small businesses which were usually of the low, unskilled level. A government official and a Buddhist nun made up the remaining categories of occupation.

Patients came to Cancer Hostel from all cardinal geographic regions of the nation as well as Bangkok and its close environs, and although these patients spoke different dialects in their home regions, it was found that whilst residing at Cancer Hostel they conversed in the Central Thai dialect for communicating with each other and with all those they came in contact within the Hospital/Hostel environment. It was noticed however, that when a group of patients gathered together and it was known that they were all from the same region, they would conduct their conversations in that regional dialect.

The allocation of rooms to those patients admitted to Cancer Hostel depended solely on the availability of space at the time of admission and was done on a 'first come, first served' basis. The exception to this, was in cases where female patients were in old age or lethargic and had difficulty in managing the steps, the staff would then place these patients in a room on the ground floor. This option was not open to male patients whose rooms were all on the second floor.

With no system in place for the specific allocation of rooms to be set aside for patients from any of the referring hospitals, meant that there was an 'even spread' of patients throughout the hostels living quarters. However, when in a position to observe the daily activities of all hostel patients, I was able to identify a number of subgroups made up of patients who attended the same treatment centre and who would, in terms of activity,
remain within those groups. That is, patients who attended the same treatment centre tended to communicate and socialize within that group. Patients within those subgroups always sat together at the dining table, went out as a group on shopping expeditions close to Cancer Hostel and would get together in one of the group member's room. In fact, it was rare to see patients from any of these 'centre oriented' subgroups join in activities with other patients. As well, on the many occasions that I was able to be with them as they rested on their beds, I began to notice that patients from the same subgroup, even though their beds may be well apart, were more likely to strike up a conversation between themselves rather than talk to patients in beds close by.

Patients' Daily Life

Because of my decision to follow only those patients who received treatment at Siam Hospital, it should therefore be noted that the majority of the accounts gathered in following their everyday life routines refers only to them and their lived encounters and is not a representation of patient life at any of the other three treatment centres.

Most patients woke very early, usually between 4.30 and 5.00 am and began the process of carrying out their morning ablution ritual, preparing for breakfast and readying themselves for transportation to the various treatment centres. Breakfast was served at about 6.00 am with transportation arriving at different times soon after, the earliest at about 6.30 am and the later vehicle at about 8.30 am.

The early start time enabled most of the patients to share the limited toilet and bathroom facilities, whilst some preferred to wash and take care of their personal needs at the laundry area instead of queuing up for the bathroom. Some would continue to lay on their beds and wait for the breakfast call, and with a mad scramble, rush to the bathroom to quickly wash their face and hands and move down for breakfast, preferring to carry out a more detailed daily toilet ritual in relatively unrushed privacy after eating.

Those who bathed early, would normally use the intervening time before breakfast to wash their clothes or simply to rest on top of their beds. Immediately after the breakfast call, most patients would take their own personal eating utensils, rush to the dining room and queue for their meal. Some patients did not make the effort of going to the dining room, being mainly those who were very sick or could not eat the meals provided.
For those who were sick, meals would be bought back from the dining room by fellow patients, whilst those who could not eat the meals provided, would wait and buy their breakfast at one of the canteens near the treatment centre or from the large number of street vendors close by.

On the completion of breakfast, most patients would return to their rooms to tidy their beds, clean their living area and generally prepare for the trip to the treatment centre. For patients who would catch the earlier transport, this time was spent gathering in the hallway of the first floor or in the small, gardened waiting area, forming small groups but rarely communicating beyond the customary morning salutations.

For those who would make the trip to Siam Hospital, there was time to rest on their beds as the transport would not arrive until much later. By 7.30 am however, many would already be gathering in the hallway or in the ground floor waiting area, where, in contrast to those patients who had left earlier on, conversations and personal contact was more noticeable amongst this larger group.

On noticing the arrival of their transport, this group would move unhurriedly toward the embarkation point, passing by the statue of the founder of the cancer institute and the spirit house at the front of Cancer Hostel grounds and as was customary, pay their respects to both entities. The same respect was directed toward the Buddhist temples that were passed en route to the treatment centre of Siam Hospital.

Whilst paying their respects, many patients would also make vows, which under normal circumstances would cover a wide range of commitments, but in these more sombre times, most would centre around the more immediate and personal side of 'living' and would usually be tinged with bravado, showing 'the fighting side' of their commitment to beat their disease and take a positive stance by affirming such actions, in that they would: be cured of cancer; have the strength to combat the side effects of radiation treatment; be free from any pain; be safe from radiation; recover quickly; and prolong their life (in one case, until a son was old enough to go into the monkhood). Patients believed that those revered objects were saksit (capable of dealing with power or capable of empowering them with the means to defeat their illness).

In favourable weather and on days when not caught in the infamous Bangkok traffic jams, it would take about ten minutes for the transport to negotiate the short distance from Cancer Hostel to Siam Hospital, arriving at the treatment centre at about 8.45 am.
On most occasions, with the vehicle having only just come to a halt, some of the patients would alight and in double quick time rush toward the treatment centre buildings in an effort to beat the other patients to the toilets. Most of those who had not eaten at Cancer Hostel would head for the canteen to buy their breakfast, whilst some preferred to purchase fresh fruit from the market at the rear of the hospital complex. Others would move directly to the rest area near the vehicle parking station to sit and wait for the days treatment activities to begin.

Although the therapeutic activities would not begin until 9.00 am, some of those waiting would sit close to the entrance of the treatment rooms and lodge their treatment cards early so as to beat the crowd that would form later. Patients who had dispersed to various parts of the hospital grounds, regrouped at the rest area just before 9.00 am.

To the dismay of Cancer Hostel patients, the system did not work the way that the early patients and I had envisaged, and it was found that patients who would arrive and tender their cards much later would be called in for treatment before them. Patients who were waiting for treatment would rely on the judgement of the staff as to what order treatment would be given and it was quickly realized that the patients from Cancer Hostel who were waiting for radiotherapy were accorded a very low priority, much to the annoyance of the Cancer Hostel patients themselves. On casual enquiry, I was informed by the staff that this in fact was the case, and that others were treated before Cancer Hostel patients who, according to one nurse, "would have nothing to do on completion of their treatment, and anyway, they would have to wait until 3.00 pm for their return to Cancer Hostel."

Treatment programmes were conducted between 9.00 am and 12.00 noon and 1.00 pm and 4.00 pm. Occasionally, during the morning session, some of the patients would be called to see the doctor for routine examinations or to be directed to another part of the hospital for blood tests or any other special investigatory activity. Some would be sent to the wards for combined treatment such as chemotherapy or intracavitary implantation with the former normally taking from 1 to 4 hours and the latter requiring an overnight stay in Ward 6.

The majority of patients, on finishing their daily radiation treatment, which normally took only five to ten minutes, would gather at the rest area to await their return to Cancer Hostel. A few would go to the market close to the hospital whilst others would find their way to the recreation area near the statue of the father of Thai medicine.
Lunch was taken at 11.30 am in an area close to the lifts of the main building. This area was really a corridor and had been set aside for visiting patients to have their meals which would normally take only five to ten minutes to finish, after which the patients would again disperse, with most of them returning to the rest area to spend the remainder of the day sitting or lying around and generally doing nothing.

For those patients who had not been treated in the morning session, it was back to the waiting area where they would again sit and await their turn to be called for treatment. The last patients would usually finish their treatment before 3.00 pm, at which time, all those returning to Cancer Hostel would assemble at the rest area in preparation for the return journey. The departure time of 3.00 pm was set to give treating staff time to complete all scheduled treatment as well as the admission process for new patients before releasing them for the return trip to Cancer Hostel.

Although a time was set for return travel and was known to the treatment centre staff, patients were usually not informed and quite often, on noticing that all those who had arrived for treatment in the morning had finished their treatment, patients would ask around among themselves and determining through consensus of opinion that this was the case, they would then ask the driver to take them back to Cancer Hostel before time.

Occasionally, after a 'patient organized early mark', a domestic would rush out and stop the vehicle, crying, "Don't go yet, don't go yet, wait for the new patient. It's not time to leave yet." The patients would then be scolded for attempting to leave early during which they would usually just sit quietly, look back sheepishly and accept the remonstration whilst muted conversations among themselves, would be aimed at fixing the blame for this transgression onto the 'ring leader' of the push for an early departure. The domestic would then produce a new patient or make them wait until any newcomer had completed the admission process and was ready to travel back with them. It was usually quite an amusing event, with things not taken too seriously and I would be left thinking of funny side of the way in which the patients had arrived at their decision to leave early. It was not quite so amusing for Mrs. Mann however, who as a new patient on one such occasion, was left behind and was forced to make the trip by taxi. Mrs. Mann would later tell of her experience during an interview aimed at learning about her referral and admission experiences. She related how:

That day [admission day], I finished treatment at about half past two, Lek [one of labourers] told me to go to the waiting area and wait there until the hospital transport came to pick up other patients. At the waiting area, I saw a few other people who I thought were patients and that they were also waiting. I didn't
ask. I didn't dare to ask. I waited there until five o'clock until there was no one else sitting there. I didn't know what to do. There was no one at the treatment area to ask. So, I took taxi, it cost me fifty baht. I was angry at having to spend my money. Later, I found out from one of the patients that they came back early because everyone had finished. They said they left at about half past two. I must have just missed the truck. It was just bad luck.

The trip back to Cancer Hostel normally took a little longer than the morning trip to the hospital, as the daily onslaught of people and the various forms of transport were already beginning to choke the roads. The hospital vehicle setting out at around 3.00 pm would almost certainly be caught up in the traffic and arrival at Cancer Hostel would be some time after 3.30 pm.

On arrival at Cancer Hostel, the patients would again pay their respects to the spirit house and the founder's statue on the way back to their rooms to freshen up after a long and exhausting day. Most patients would retire to their beds, to lay quietly, relax and hopefully regain some of the strength that the day had taken from them. Some of the more energetic would collect their washing from the drying area, whilst others, who had only a limited amount of clothing with them or as in some cases, just the clothes they stood in, would wash these items in preparation for use the following day. Newcomers, who had been assigned to stay at Cancer Hostel from Siam Hospital would wait for the staff to allocate them to a bed area.

Dinner at Cancer Hostel was served at 4.30 pm and the patients would begin to collect in the dining area soon after the meal call which was really a piercing blast from a fire alarm and which on more than one occasion made me jump in fright as I was not expecting such a loud, shrill noise just to summon the patients to dinner. It did not seem to bother the patients however, who would show little or no emotion toward this peace shattering sound.

At Cancer Hostel, patients took their time to have their evening meal with most of them arriving at the dining hall with their own eating utensils to join the queue whilst quietly chatting amongst themselves before being served by the usually boisterous cook and her helper. Some brought along extra food which they had purchased from the hospital or from shops close to Cancer Hostel. After queuing for their meal, they would sit together within their groups and share the food which they had bought that day.
Patient activity after the evening meal would vary, as some preferred to rest on their beds whilst others would sit in a group on the floor and take enjoyment from sharing a snack and recounting their days activities through animated conversation. Some patients would enjoy a short visit to the recreation area before the clouds of mosquitoes drove them back to their room. Very few cared to watch TV because of the inconvenient location of the old black and white TV set. With little else to do, most would wander back to their living areas and whilst sitting on their beds or on the floor close by, they would engage in more subdued conversations on the days events and what possibilities the morrow would bring.

As the evening darkness closed in around them, some patients would spend their time standing by the windows, and stare out at nothing in particular, their faces showing signs of loneliness and boredom. All patients would be in bed by 8.00 pm, with some continuing the conversations started earlier which usually trailed off to nothing and whether or not sleep would come, peace would settle over the patients’ quarters with the only sounds coming from the outside street traffic and for some, the noisy ceiling fan.

On weekends, about half of the patients would return home or visit relatives who lived in the Bangkok area. For the others who would have to remain at Cancer Hostel, their routine daily life was a little bit different and a lot slower than the hectic course of events experienced on treatment days. They did not have to get up early and with no rush to get ready for the trip to the hospital, many patients preferred to lie in bed until the breakfast call, then hurry to wash their face before making their way to the dining room.

After breakfast, most of the patients would return to rest in their room, whilst only a few were happy to spend time at the recreation area before the morning freshness gave way to the heat of the day. With the remaining meal times at 11.00 am and 4.30 pm, the patients would again gather in the dining room at those times to partake in lunch and dinner.

If patients had the means to return home during the weekend break in treatment, the majority would most certainly have done so, and whilst all patients had expressed their desire to return home during these breaks, they also realized that they could not very well afford the costs involved. As well, some patients were too tired to travel, whereas others were afraid of becoming lost along the way. A number of patients were more concerned with the domestic chaos they thought would greet them if they did return home and knew that they could not just sit and ignore that situation and would subsequently, have no time to rest. They were also concerned that they would not be able tolerate the treatment of the following week if they did return home.
It was quite noticeable that very few relatives came to visit the patients during their stay at the hostel, as it was equally noticeable from the conversations held with the patients that most understood why this was so. Mrs. Wanna told of her own understanding:

I don’t feel sad or sorry that no one comes to visit me, although I do miss them [her husband and children] very much. I know that they have to work just to survive. We are very poor. If they stopped working, they would have nothing to eat. Now, without me they have to work harder. Really, I don’t want them to come, they are not familiar with the way and if they did come, I would worry about them getting lost and I would only stop worrying when I heard that they had arrived back home safe and well.

For the relatives of the Cancer Hostel patients, the decision to visit their kin posed a number of problems, as well as presenting a rather worrying situation for the patients themselves. Most relatives did not dare to come alone as they were afraid of becoming lost in trying to find their way through Bangkok’s notorious urban sprawl. They would therefore be compelled to make arrangements to either travel as a family group, or team up with a number of close friends and acquaintances. In cases where relatives had decided to visit their sick kin in Cancer Hostel, those relatives (following normal Thai Protocol) would feel obliged to play host as well as taking responsibility for all expenses incurred, including transportation and meals. For this reason alone, many patients would rather that they had no visitors. Although these patients would express their delight at having friends or relatives visit them, they would also exhibit signs of having mixed feelings about their coming, which was the case for Mrs. Boontoung, who after bidding farewell to one such group of visitors, watched as their truck manoeuvred out of Cancer Hostel to begin the long trip back home. She remarked:

... they’re not all my family. My husband didn’t come. My daughter told me that he had to work in the rice field to earn his days wages. The man who drove the truck is the headman of my village. My mother asked him to take her to visit me, because he knows the way into Bangkok, then he asked his wife and his friend to come along. They are not going back home straight away, they are going to stop at some of the tourist spots on the way. I am very happy that they came but I am also concerned over the money that my mother had to pay for this trip, including the petrol and meals on the way. Really, they cost a lot, and as my mother had asked them to come along, she had to pay all expenses. I told my mother not to come again. I told her it will not be long before the treatment is completed and I will be going home. I told her to save her money and if she wanted to get in touch with me, she could ask my sister-in-law to come to visit me
There was the occasional weekend or public holiday activity organized by volunteer groups such as the Buddhist student society who came to visit the patients, especially on Buddhist religious days. They would come to present small gifts to the patients and talk with them about the Buddha's teachings and give psychological support in order to help them cope with their suffering.

People from all sections of the community would be allowed to enter Cancer Hostel at those times and move freely among the patients without hindrance from any member of the staff. The main reason for most of these individuals visiting the hostel, was to make merit by giving out small gift items and money to all members present at the time. These occasions were usually to mark a special event, such as Buddhist religious days, birthdays or to show gratitude for recovering from an illness and as a sign of repayment of vows made during that illness by making merit.

These people would bring toiletry items such as soap, tooth brushes, tooth paste, toilet tissue and the like, as well as money and other donations which they would distribute amongst the patients. Normally, the housekeeper would be informed by those people of their intentions which she would then pass onto the patients. After hearing of a planned weekend visit, patients would sometimes postpone their plans to go home over that weekend and remain at Cancer Hostel.

There were also visits from the cancer nurses society who found the time to visit Cancer Hostel patients. The objective of these visits was to provide patients with an opportunity to ask questions about their illness and their health in general as well as their treatment. Visits were scheduled for every last Sunday of the month with visiting time being from 9.00 am to 11.00 am. However, over the six months period that I was in Cancer Hostel, only two visits were made and during one of these visits I had the opportunity to observe the event first hand.

The number of the visits had declined as the number of nurses who volunteered their time to undertake this task had also declined. One member of the society, a staff nurse from the Radiological Nursing Division of Siam Hospital, told how she had earlier found the time to visit patients at the hostel, but as she was now committed to playing tennis every Sunday, could not find the time as before. Because of the irregularities of these visits, patients were not given any prior warning as to when the next visit would be. Therefore, it was usually a case of where the domestic staff would call the patients from their rooms
to attend an information, question and answer session concerning their illness and treatment. On this observed occasion however, many patients showed a reluctance to move from their rooms, and were then subjected to one of the domestic staff pointing at them and calling their names, beckoning them to come out to meet the solitary nurse who had arrived.

After the patients were seated around one of the tables, the nurse introduced herself before telling the gathering, "I am here to give you information about your illness and treatment and any other related matters that you think you should know about, but did not have the chance to ask your doctor." Pausing to scan the patients for any sign of reaction, she then asked, "Does anyone here have any questions?" which was greeted with absolute silence, with not a sound coming from the patients. The nurse, to her credit, persevered with trying to coax the patients into speaking out, but in spite of her efforts, she was mostly unsuccessful.

Although still remaining quiet, patients showed an attentive attitude and a willingness to listen as the nurse carried on with problems relating to the side effects of radiation therapy and how patients could alleviate the severity of those effects. It was not until she spoke about drinking a lot of water to lessen the severity of cystitis that Mrs. Wanna spoke out, saying, "I can't do that because I have no water to drink, I have no money to buy a lot of water." This reason for not having enough drinking was unanimously agreed by all patients. It was seen from her puzzled expression, that the nurse did not understand, she then asked about the water provided by the hostel and why the patients had to buy their water. After realizing that drinking water was not provided for the patients, the nurse told them that she would ask the housekeeper if there was anything that could be done to help in providing that basic commodity of life. However, I later found that the nurse did not prosecute this matter with the housekeeper when talking to her at the conclusion of the meeting.

Another topic that patients thought worthy of bringing to the attention of the nurse, was their difficulty in maintaining an appetite that was affected by the on-going radiation treatment. The nurse suggested that patients should eat light food in small amounts and to make a habit of eating more frequently. She also suggested that patients should store the food that they received and to eat when ever they felt hungry outside the normal meal times. This final bit of advice made the patients sit up and listen more intently and I noticed many patients having a little giggle. Mrs. Sar, who was sitting close to me, whispered, "She should put this proposal to mare barn [housekeeper], the one who looks after the place and find out whether or not we are allowed to store food here."
The meeting lasted about one and a half hours, after which the nurse dismissed the patients, but instead of moving off, they remained behind to help the nurse fold the chairs and place them at the rear of the room. On returning to their rooms, patients began to talk about the real problems that they were encountering and which I thought, should have been brought up in the meeting.

This behaviour had become a regular pattern with the patients, whereby they shared their more intimate experiences with each other, but made very little reference to any of the nurse's responses and suggested remedies for their problems, or for that matter, to any other suggestion that may have been of some benefit to them. Some patients showed a complete disinterest in talking about any of the points covered in the meeting and preferred to remain silent and more than likely, forgot all about it.
CHAPTER 7

THE THERAPEUTIC PLACE

Siam Hospital

Founded over 100 years ago, Siam Hospital is the nation's oldest medical institution and is located in one of the older suburbs of Bangkok, the capital of Thailand. The present maze of buildings are sited on the grounds of the original hospital with some of the early structures surviving and which are still in evidence today. The hospital has seen many changes in its development and is still undergoing change, not only in its outward appearance through its many building programmes, but also in finding its rightful niche in the overall structure of health education. Maha University, originally an institution built around the medical school affiliated with Siam Hospital, has today become the focal controlling body with the Faculty of Medicine being just one of fourteen faculties under its control.

Under the new administrative organization, Siam Hospital, as part of the Faculty of Medicine, serves three major interrelated functions, those being, the provision of a centre for patient care, a site for medical and health related education, and a locus for on-going clinical research. The institutions charged with providing those functions are staffed by personnel drawn from various departments of the Faculty of Medicine including the Medical, Surgical, Out-Patients, Radiological, Nursing and other departments, with each institution having the responsibility of providing care for patients in their own specific areas.

At the time of this research, Siam Hospital was an up-to-date, modern, public hospital having a 2000 bed capacity which catered for all types of cases. Those familiar with health care services in Thailand, regard Siam Hospital as being pre-eminent among all others in the provision of treatment and care, as well as providing the best facilities available in any field of medicine.

Nursing in Siam Hospital has also changed, as in the past, the School of Nursing was part of the structure of the Siam Hospital and was established not long after the School of Medicine. At that time, the School of Nursing took responsibility in both the provision of nursing education for the nurses of Siam Hospital and the control of nursing care given to
patients admitted to Siam Hospital. In 1972 however, following the further development of the education system of Maha University, the School of Nursing was divided into two institutes, that of nursing education (Faculty of Nursing) and nursing services (Department of Nursing). On the table of organization, the Faculty of Nursing was linked directly to Maha University and was responsible for the education of nursing students of Maha University. The Department of Nursing, being responsible for nursing services in the provision of nursing care within Siam Hospital, was linked with the Faculty of Medicine of Maha University. Although these institutes maintained separate administrative bodies, they continued to work in close co-operation with each other through the various appointed committees.

The Radiological Department

The Radiological Department of Siam Hospital maintained control of the overall activity within the department and was responsible for all matters regarding the treatment of cancer patients who were assigned for radiation treatment. The department occupied four floors of the ten storied 'A' building located centrally within the hospital grounds with the ground/first floor being allotted to the administrative services, medical and nursing staff offices, a nursing treatment room, meeting and conference rooms, a staff rest room, an X-ray/radiograph room, with the three radiation treatment rooms being interspersed throughout this level. Another radiation treatment room and a film storage room were located at the basement level with the entire second floor of the building being allocated to the X-ray investigation unit. The ward section of Ward 6, located on the sixth floor, was comprised of an Eastern and Western wings being separated by the lifts and stairwells. The Eastern wing included a day treatment room for out-patients which provided chemotherapy, blood transfusion and intravenous infusion treatment, with the private and public bed, male ward area taking up the remaining floor area. Western wing facilities were exclusively for female patients, with the intracavitary applicator inserting room and the adjoining intracavitary radiation treatment rooms to one end, whilst five semi-private, partitioned rooms and a twenty bed, open ward for public patients was at the other.

Whilst waiting to undergo treatment at Siam Hospital, Cancer Hostel patients were compelled to spend most of their time in the ground floor radiation treatment area close to the patient drop off and transportation parking area at rear of the building. The transport parking bays and open air rest area were at one end of a covered walk-way which divided the hospital building complex down its centre, allowing access to the many corridors and rooms along its length. The entrance used by the early arrivees from Cancer Hostel was located a little way down the walkway and opened onto a maze of connecting corridors
which gave access to the ground floor of the Radiological Department. Wooden benches lined these corridors which served as rest areas and were used by the patients who were either waiting to see the doctor or to be called for treatment as well as for other non-treatment related services.

The Staff

The personnel who staffed this department were drawn from two other, separate departments of Siam Hospital, with each department retaining supervisory control of their members. This meant that staff personnel, including the doctors, radiological physicists, radiological technicians, the sociologist, and office staff, were under the supervision of the Radiological Department, whilst staff providing nursing care came under the supervision of the Radiological Nursing Division, of the hospital's Nursing Department and included the nursing staff, practical nurses and the one nursing aide. Control over labourers was divided between these two departments.

Although it would appear from the above line of organization that the nursing staff had the authority to regulate the care given to patients under their charge as well as being in control of their own patient care, this was not the case. This point will be covered later in this chapter under the section devoted to 'The Conflict'.

THE DOCTORS

During the period of this research, the Radiological Department could call on the services of nine permanent staff doctors including the director of the department and the three resident doctors. When patients first visited the department, they would be assigned to any one of the doctors who happened to be on duty at that time. The initial visit was for consultation, assessment and discussion of the role of radiotherapy in his or her treatment programme. Also, during this visit, a primary staff doctor would complete the patient history file and on performing a physical examination a radiation treatment plan would be prescribed.

In most cases, patients' diagnostic studies and pathology reports had been reviewed at the Out-Patient Department or other referring departments including Surgical and Gynaecological Departments before their consultations with doctors of the Radiological Department. As well, in some cases, the results of diagnostic studies and pathology reports would be presented for discussion at a twice-weekly, multidisciplinary tumour
conference held at the tumour clinic of the Radiological Department. Some patients however, arrived at the hospital with completed pathological results from the referring doctor, which in most cases would make the assessment process unnecessary and allow the doctor to prescribe treatment based on the already available results.

After having offered the treatment and in most cases, receiving no objection from the patient, the schedule for the commencement of the treatment would be made by the doctor. Commencement time for radiation treatment varied from case to case, and with no set guide-lines to follow, would depend entirely on the doctors decision. Usually, after radiation therapy had been prescribed, the doctor would ask the patients to return home and come back to commence their treatment two weeks later. The reason for this practice of delaying the treatment, as explained by Dr. Rord, was "to give them time to boost their physical condition in preparation for radiotherapy treatment." The patients however, were not informed of this reason and did not understand why the doctor had asked them to go home and come back again in a fortnights time. Mr. Pratin told how:

... I was given appointment times for a range of tests which took me about half a month to complete and which forced me to travel to and from my house four or five times to keep those appointments. I still had not commenced any treatment at that stage and I had to wait at home for another two weeks before I actually started. It was really a waste of time. I had really wanted to commence treatment as soon as possible because I was afraid that my disease would spread.

The patients' physical condition was not the only factor that influenced the doctors into making decisions as to when radiation treatment should commence, as there were other considerations which had to be taken into account when assigning treatment schedules, including the availability of treatment apparatus and the number of other patients scheduled for treatment. A number of doctors were afraid that some patients would 'run away' if treatment was not initiated almost immediately, and so, those patients adjudged as being likely to abscond, would commence radiation treatment on the day of their first visit.

Concern for the patients' social well-being was never a factor in the consideration of the treatment schedule, thus the patients often began their treatment in a stressful frame of mind. Examples of this were found in cases where patients, in keeping their appointment with the doctor to learn of the test results, were informed that they would have to start their treatment immediately.
As a result of this early scheduling, a number of patients, having travelled alone from remote areas, had no way to communicate with their families to inform them of the situation and were forced to suffer a great deal of unnecessary anxiety.

To the doctors, in their considerations of the treatment schedule, the patients' social life "of course, does present some problems to the patients" but, "are less important than their health problems and not as difficult to solve." At this juncture, the doctors appeared to be only concerned with the immediate or 'surface' problem and treated the social needs of the patients as something that could interfere with or obstruct the treatment programme and make it difficult to continue that programme over an extended period of time.

This problem, in the doctors eyes, would be solved during the normal course of events and they would cite the welfare services already in place and which were able to give support to the patient and provide for their particular needs. This of course, was a reference to Cancer Hostel where the provision of free accommodation and meals along with the hospital's support in providing a free transportation service, was seen by the doctors as the answer to any problem the patient may encounter.

Telling the Patients

The practice of withholding the true diagnosis from the patients was the accepted norm among the doctors of the Radiological Department. Usually, the doctors would inform the patients about the treatment offered without mentioning the true diagnostic outcome of the clinical investigation. It was also customary practise for the doctors to only emphasise the necessity of the treatment offered and the positive therapeutic effect of that treatment. This can best be illustrated by the following discourse between myself and Mr. Pratin, a cancer of the esophagus patient:

R: Did the doctor say anything about your diagnosis when you went back to him for the results of the earlier visit?
Mr. Pratin: He [the doctor] said, "You must receive radiotherapy treatment". He didn't tell me anything else. I already knew about my illness, so I didn't ask any more about that. I overheard the doctor say, "Tumour of the esophagus" and that when I swallowed it pressed against the esophagus and would not allow food to pass through. He told me that radiation could shrink the tumour and that I would be able to eat again. I asked him about surgical treatment and he said that it could be done, but I would not be able to talk afterwards. So, I elected to undergo radiotherapy.
Doctors would only inform the patient of the true diagnosis in cases where the patient, having been scheduled for radiotherapy, refused to accept the treatment offered, thus forcing the doctor to reveal the real reasons why they were to undergo that type of treatment. Doctors who found themselves in this kind of situation, would normally react in an aggressive manner toward the patient. As Mrs. Utorn’s husband would later recall:

She is very stubborn and insisted on not having radiotherapy. The doctor here [Siam Hospital] called Utorn, her father and I into his room. Then, in an effort to get her to make a decision, the doctor told her, in a rather straightforward manner, that she had cancer and that she must undergo radiotherapy treatment. There was a chance of survival if she underwent the treatment, if not, she was going to die.

Usually, a positive prognosis was communicated to the patient prior to the commencement of treatment. The doctors in these cases, were most likely to tell their patients that by undergoing radiotherapy the disease could be cured.

In all cases, the doctors were aware that the patients’ diagnosis pointed to malignancies, and that in many cases it was already into the late stage. Knowing this, as well as the likely course that the disease would take and its eventual outcome, doctors were still reluctant to inform the patients as "it would upset them and force them out of the medical treatment system and into attempting to find an alternative treatment."

What the doctors normally endeavoured to do in these situations was to ensure, in conveying to the patients that their illness could be treated and cured by the means available at Siam Hospital, that it was offered in a manner that would not alarm the patients about their bad prognosis. However, only one patient reported that the doctor told of the diagnosis as well as the prognosis. In this case, Mrs. Nunn told of a most harrowing experience which began when she returned to accept radiation treatment after having ‘run away from it’ for a year, and was referred directly to the Radiological Department, where the doctor, known from her previous visit, conducted a PV (per vagina) examination after which he told her bluntly that in her case it was all too late because her cancer had gone too far and that she would be dead within six months.
During the course of treatment, true diagnoses were not communicated to the patients. As well, in my observations on doctor-patient interaction during consultations, I found that the subject of diagnosis was never brought up or talked about. Most doctors concentrated on the job of assuring themselves that the treatment plan was under control or 'on track' and only conversed with the patients to emphasize the importance of them continuing with the treatment programme.

One example which illustrates this style of interaction, was observed in the case of Mrs. Mai, who had been receiving radiation treatment for about one week and was waiting to see the doctor for her regular check up. After waiting in the queue for nearly two hours, she was finally called in to see the doctor. Mrs. Mai walked into the room, wai (paid her respects to) the doctor and sat on a chair in front of him. Dr. Nit initiated the conversation by asking her, "How do you feel?" and without showing any intention of accepting the answer, he busied himself in reading the patient's treatment file. Spending about thirty seconds in glancing through the various notations, Dr. Nit broke the silence, saying "Everything seem alright, let me see the skin markings." Mrs. Mai undid the buttons of her shirt and exposed her chest area to show where the skin had been marked. After quickly looking at the markings, Dr. Nit said, "The marks are still intact, we don't have to remark today." Then, on making a few notations in the treatment file, "Continue RT [Radiation Therapy]", he closed it and told Mrs. Mai to, "Continue with your treatment." Mrs. Mai stood up and again wai the doctor, then walked out of the room. Outside the doctors room, Mrs. Mai, who was rather despondent, remarked:

I am a bit disappointed that the doctor did not give me any information about my illness and treatment. He didn't even tell me how long my treatment would last. Doctors should tell the patient about their treatment, at least the duration of the treatment. If they did, I would at least be able to contact my husband to pick me at the right time.

For Mrs. Mai to ask questions concerning her illness would be considered as "Not an appropriate manner for the patient to act", or "Not the Thai way." On the other hand, when patients came to visit the doctor and were faced with the dilemma of not knowing anything about their illness situation and feeling frustrated over not receiving any information on the matter, any questions directed at the doctor in relation to their illness, were usually met with some doctors pretending not to hear and change the subject, whilst others would simply not answer the question and reassure the patient that their diagnosis was not cancer.
Patients would often comment that most doctors concentrated solely on the job of prescribing the treatment rather than providing explanations on the cause of the problem and were seen therefore, as someone who was able to prescribe medication to relieve their symptoms, but who failed at being able to offer any form of information to relieve their anxiety.

**Attitude Toward Alternative Treatment**

Most doctors of the Radiological Department of Siam Hospital actively opposed the traditional curing practices. This attitude was clearly expressed by Dr. Vena, head of the department, in an article written for the Thai Journal. In that article, Dr. Vena proposed a number of measures to help solve the cancer problem in Thailand. One such measure called for the eradication of traditional healers in suggesting that:

Serious efforts should be made to eradicate those quacks who openly advertise traditional medicine and magic methods for treatment of all forms (and all stages) of cancer. These quacks not only drain a large sum of money (often a fortune) from cancer victims, but also kill cancer patients by deliberately taking them away from effective treatment in modern hospitals, particularly during the early stage when cancer can be most effectively treated.

When dealing with tradition-minded patients, most doctors took offence at the patients' unwillingness to commit themselves to the single form of treatment that was prescribed by the doctor. These doctors emphasized that simultaneous dependence on modern and traditional remedies could have only negative consequences. In a hand-book for radiation patients, written by doctors of the Radiological Department, it was pointed out that herbal medicine would not only retard the healing process, but cause diarrhoea and vomiting. Patients therefore, were not allowed to take any form of herbal medicine whilst they were undergoing radiation therapy. It was suggested however, that if patients really wanted to take herbal medicine, they were to do so, only after completing the treatment programme. The reason for this suggestion, as explained by one of the doctors, was "to keep those patients within the modern medical system."

**SOCIAL WORKER**

After the initial screening, patients who needed support would be sent to see the social worker who made the final decision as to who would receive support and what kind of
support it was that the patients really needed. To ensure that social welfare resources would only be provided to the needy patients, the social worker would employ 'tough tactics' in the selection methods.

The tough approach used by the social worker in the selection of patients to receive support, included the thorough questioning of the patients in an attempt to get them to disclose their true social and economic status, as well as pressuring them into accepting sole responsibility for their problems. This had the desired effect of instilling into the patient a feeling of guilt and desperation in their acceptance of social support. For many patients, the tactics employed by the social worker in her approach toward the question of money, did nothing but humiliate them. Some patients however, had to put up with this situation in order to obtain help. Others felt it was too much for them to cope with, preferring to drop the request for help rather than continue with that form of inquisition. Mrs. Sumran, one of those patients, expressed her feelings when asked about her experience:

I was really angry and upset, she told me that the hospital had only a very small amount of money available and asked me to help the hospital by paying some portion of the cost of medicine. I told her that I really had no money, she then asked me about my family and could any of them help. Oh, my relatives are very poor and they have just enough money to feed their own family. When I insisted that there was no one who could help me at this stage, she kept on reminding me that the hospital had already helped me a lot, that I had received free treatment and a free place to stay, and that I should take responsibility for a small amount of the cost of the medicine. I felt most distressed and humiliated over her continually reminding me of this. So, I told her I did not want any help and that I would buy the drugs myself. She gave me my prescription back, I didn't buy the drugs though.

Patients were sometimes judged as qualifying for social support on what was contained within the personal profile section of the patient's hospital file and notations of this decision were made accordingly. As was seen on a number of occasions, these decisions were not always the correct ones with many examples of poor judgement being found in later researcher/patient interviews. One example of this involved a patient who was receiving full 'free' social support although he was a very wealthy man. The patient concerned, dressed like most other rural workers in simple, dark, loose fitting cotton attire and had the same weather beaten appearance that indicated he was from a rural environment. Mr. Pratin explained:
I was not asked if I could afford to pay for the treatment. None of the questions asked by the doctor were concerned with my financial status. He must have thought I was poor from the way I dress and recommended that I receive support. The social worker did not ask any further questions on the matter. I didn’t say anything to them, just answered the questions that they asked or kept quiet. If I was asked to pay for the treatment and the drugs, I would.

Under a new policy set in place by a recently installed hospital administrative body, cuts were made to the everyday running expenses of most of the hospital’s departments. This policy affected the way in which hospital staff went about their work and was keenly felt by those who were in contact with the public. As the social worker pointed out, "We have to ask the patients to help themselves as much as they can, especially in relation to the payment of treatment fees."

RADIOLOGICAL PHYSICISTS AND RADIOLOGICAL TECHNICIANS

These staff members played an important role in the technical delivery of the prescribed treatment. Radiological Physicists were involved in the simulation process which was carried out prior to the actual treatment with the aim of defining the treatment target. As well, they were responsible for ensuring the accuracy of daily 'set ups', and the protection of healthy tissue from radiation injury.

Radiological Technicians were responsible for the actual delivery of the daily radiation treatment dose to recipient patients. It was found, that although these staff saw the patients on a daily basis, there was no real contact with them, as most technologists concentrated on the job of monitoring the computer at the control station, the positioning of patients and the treating apparatus in the treatment room.

THE OFFICE STAFF

During my time covering the treatment environment, doctors employed untrained staff to prepare paper-work or to set up the medical clinic within the Radiological Department. Their work includes the preparation, collection and registration of the patients' medical records in readiness for circulation within the department. The doctors would use these records for their daily treatment schedule during the regular operation of the tumour clinic as well as for the weekly doctor conferences.
One of the untrained staff members was promoted to fill the position vacated by a trained nurse who retired from the position of 'cashier'. The position called for her to be solely responsible for the collection of the treatment fees as well as giving health education talks to patients receiving treatment. It was the idea of the head of the Radiological Department to promote an untrained staff member into that position, feeling that it was unnecessary to have a trained and qualified nurse filling an administrative slot.

There were times when this member felt that the position, with its inherent responsibilities, was far too much for her. She was also aware that her qualifications were unsuited for the position and mentioned that the job of giving health education should be provided by the nursing staff. However, she handled the task of health education as best she could from what she had learnt during her ten years service in the department and from what she could remember of the lessons given by her predecessor, as well as from what she picked up from the books she read.

The 'cashier' explained that during the health education lessons, which covered such topics as, nutrition; practical, expected behaviour in relation to personal health; and complications whilst receiving treatment. There were times however, according to the 'cashier', that some questions posed by the patients could not be answered and that she would later ask the doctor to clarify those points. In practice, I found that the health education lesson was nothing more than a short conversation between herself and the patients that briefly touched on those points mentioned and was of little value to the patients concerned.

THE LABOURERS
These were the lowest ranked members of the staff employed by the Radiological Department and they were mainly concerned with the cleaning and tidying of the radiation therapy department area before and after treatment hours. As well, during the hours that treatment was conducted, these workers were used to carry out various other functions as directed by any of the department's staff, such as, calling patients from the waiting area in for treatment; helping radiological technicians in positioning the patients and the machine in the treatment room; search for patients' files if they could not be located within the immediate office area; direct patients to the various facilities for further treatment or investigation; and the transportation of the patients either by trolley or by wheelchair to and from the treatment room. Within this kind of work, the labourers had the opportunity to contact patients on a regular basis, and possibly, more than any other group, the chance to monitor any alterations in either the physical or emotional status of the patients. On a
number of occasions, it was observed that when the need arose, these staff members were able to speak to the patients and enquire if they needed a referral to see the doctors for management of the problem. They in fact became the 'go between' in situations where patients had either held back from reporting their problem or where their altered condition had not been noticed by the medical staff.

THE NURSING STAFF

The nursing staff who were assigned to care for the cancer patients during the course of their treatment programme, were organized into two groups. One group of nurses were charged with the care of the patients during the time that they were actually undergoing treatment, whilst the other group were responsible for patient care once they had been admitted to the ward. Both of these groups were under the direct control of the Radiological Nursing Division of the hospital’s Department of Nursing.

Under the organizational structure, Miss Pen, the head of the Radiological Nursing Division, had a direct-line relationship with the director of the hospital’s Department of Nursing. Miss Pen met with her supervisors on a weekly basis and would be be joined at other fortnightly meetings by the departments head nurses. These meetings were called primarily to discuss policy and procedural changes and their implementation within the department. According to Miss Pen, the supervisors were the first-line managers who were responsible for the daily running of the sections to which they were assigned.

Each head nurse was expected to communicate information from these meetings to the nursing staff of her unit. Mass meetings of the different levels of nursing staff were held three or four times during the year. These meetings were called to provide 'in service' education for all staff and to provide a forum for them to ask questions concerning general nursing conditions. When required, the head of the division would announce important policy changes at these meetings along with the announcement of specific events which would effect the nursing staff.

Most of the nurses who were assigned to the treatment section had at one time worked as part of the ward section. Later, when position vacancies occurred or when there was an increase in staff numbers, nurses who were with the ward section and who had difficulty in coping with the shift rotation system and its effect on their married life would be given priority in filling those positions with special consideration given to pregnant nurses.
The vacated positions in the ward section would be filled by the new, recently graduated nursing members. However, this system was seen as unfair by some nurses who remained working in the ward section, especially those single, senior nurses and married nurses who had no family. One of the single nurses confided in me that:

It is not my fault that I am single and should not be used as a mark against me. I will probably have to work here for the rest of my working life. No one wants to work here [Ward 6]. If I had the chance of moving to the treatment section, I would.

It was not difficult to understand why nurses preferred to work in the treatment section rather than in the ward section as there was a marked difference between the working conditions of these two sections. It was widely known by most nurses that it was more comfortable to work in the treatment section than in the ward section, as the work load was a lot less, with no shift work, no weekend work and where there was less risk from exposure to radiation.

Generally, the tasks assigned to the nursing staff of the treatment section included, providing assistance to doctors in both the treatment rooms and doctors examination rooms; providing direct nursing care such as, dressing, injection and the administration of intravenous infusion; as well as staffing the sections reception facility.

Nursing roles were often blurred and there was much overlapping of activity of all role groups. Practical nurses and the one aide carried out some direct patient care, including the more complicated nursing tasks. The aide, for example, was used in the management of even the most complicated ulcers and practical nurses were used for the monitoring of intravenous blood transfusions and fluid infusions, as well as the removal of empty applicators on the completion of intracavitary treatment.

Although not prepared by their training programmes to provide this care, practical nurses and aide were sometimes called on to do so when staff nurses were not available. This overlapping of role functions, was viewed by most staff as being inappropriate, only in the sense of using unqualified staff to do particular jobs. However, the question of whether a function was appropriate or not, did not arise when the job had to be done and only certain staff were available. Miss Tum (the nursing aide) commented, when observed dressing the ulcerated chest of one of the patients:
As you can see, this ulcer is rather severe and complicated, it should be the job of the nurse or one who is trained in these procedures. But, in the past, there was only one nursing staff here [nursing treatment room] and I was assigned to help her. So, I helped by doing the dressings whilst she did all the injection, took blood samples, and so on. However, even when more staff came to work in this department, I still did this job. Not all the time though, only when a staff nurse was not available. I can do it. I've worked in this place for nearly twenty years and I've had plenty of experience at it. I have done this many times. So, I know how it is done.

This situation was indicative of staff functions within the treatment section to the point where, except for variations in dress uniforms denoting nurse status, the tasks of nurses, practical nurses and the aide was indefinable.

OTHER STAFF

There were many staff personnel outside that of the Radiological Department with whom patients interacted during their course of treatment. This included the staff of the pathological clinic, where patients were given their blood tests and urine tests; pharmacists, where patients went to buy prescribed drugs; and the drivers, who were responsible for patients' transportation. However, most of these staff members had little effect on the patients, except the drivers, who made some impact on them.

Of the ten drivers who were employed by Siam Hospital, only two were assigned at taking turns to drive the truck or small commuter van for Cancer Hostel patients. Both drivers held negative attitudes toward Cancer Hostel patients with both harbouring fears that cancer was a contagious disease and that they could become infected by just being near the patients. The older driver, although fearing cancer and worrying that he might contract the disease, did not show his feelings or exhibit any other mannerism to make the patients think that he objected being near them. In contrast, the younger driver, who had only been in the job for six months, mentioned that he had no feeling about cancer. However, the way in which he treated the patients was a clear reflection of his true feelings.

My first inkling of this negative attitude of the younger driver came from the patients themselves, the point being brought up by them during one of our everyday conversations. The day's topic had swung around to the subject of rejection and after listening to the patients' views, I asked them, "What gives you the idea that people reject you?" Patients were quick to point out the case of the younger driver as an example and told how he never allowed patients to sit in the front seat and did not turn the air conditioning on when he drove the small van. Later, I noticed this to be true and just as
the patients had explained. The driver locked the off-side, passenger door and would not unlock it when patients asked to be allowed to sit in the front seat, even on days when either vehicle was crowded. However, if I asked, he would unlock the door for me and let me sit in the front with him. I did not ask him directly as to why he locked the door, as I had begun to notice that he seemed not to want to speak to me as he had done in the early days, and our communication had become two or three word dialogues. It would, I think, be safe to accept one patient's explanation of why he did not operate the air-conditioning. As Mrs. Kesom theorized:

I think he is afraid that he will catch the disease from us, he never comes near us and never talks to us. You have noticed that even on the hottest days, he will never turn the air [air-conditioning] on, I think that he doesn't want our smell to circulate around the vehicle. He probably thinks that he can get the disease by smelling it.

Functional Aspects

In the treatment section, there was no simple daily routine that could be seen as remaining constant within an overall environment where activities changed from day to day. Interpersonal relationships ebbed and flowed, with external influences from other departments along with other social circumstance being a regular source of change. Under normal circumstances the treatment section operated on a Monday to Friday basis with this 'business conducted on weekdays only' principle being strictly adhered to and with no efforts being made to utilize the weekends to make up for lost treatment time. This usually meant that any commitment to external activities such as religious events, hospital fund raising functions and so forth, which involved the staff, saw the entire section 'shut up shop' and cancel any remaining treatment appointments, or in some cases, the entire day's treatment would be cancelled and re-scheduled to the next working day. Although they were informed of any such change it would still remain a most frustrating time for the patients who usually found it hard to adjust and to their way of thinking, it was a waste of their time and would ultimately result in pushing their completion of treatment date back even further. In sharp contrast, very little change was seen within the daily activity of the ward section and except for the occasional VIP visits or the odd times that saw equipment failure, the daily life of all involved went on as normal.

THE CONFLICT
In a meeting with the head of the Radiological Department, during which I outlined my research interest and expressed my desire to conduct part of my field study in her department, I became aware of the conflict which existed within the departments higher echelons. It became quite apparent during the conversation that flowed from our initial discussion, that she harboured a negative attitude toward the nursing staff of her department.

The department head also expressed her belief that there were too many nursing staff allocated to the treatment area, which to her was:

... unnecessary and costly. In the past there were only three nurses working here, one in intracavitary room, one in chemotherapy room and one at the reception counter. But after the appointment of the present head of Radiological Nursing Division, the number of nurses working in this area was increased to twelve. It is not necessary to employ more nurses here, because at the moment we have enough trained staff to do the work. I don't know what the nurses do, I have no idea, sometimes I see them packed into the chemotherapy room, whilst at other times I hardly see anyone at all. On paper, it shows that there are twelve nurses, but I don't know where they are. You will see for yourself whilst you are here.

Miss Pen, the new head of the Radiological Nursing Division, informed me that she had tried to implement a patient education programme within the treatment section, but Dr. Vena did not think that it was necessary, and it was Dr. Vena who made the programme difficult to continue. An example was put forward by Miss Pen:

In the past, there was an empty desk in the corridor alongside the social worker's desk where the nurses used to instruct the patients. However, that desk was removed on the order of Dr. Vena and now there is no place for the nurses to teach the patients.

To provide me with further information about the work in the department, Miss Pen called for one of the senior nurses to give her opinion. This nurse agreed with her and gave the following account:
The doctors in this department are not very sympathetic toward the patients. They have told us [nurses] that if the patients ever come to see them whilst they were in conference, to tell them that they can't see them today, make another appointment and to tell them to go back home. In these cases, it is the nurses who have to face and deal with the patients, not the doctors.

When talking with the nurses about the conflict of interests between the two department heads, it was generally agreed, that it was difficult and uncomfortable to work under the existing conditions. One of the nurses commented, "An example of this, is that for the sake of the patients I have tried to teach them about their treatment, but I've had to do it secretly and out of site." Mrs. Pranee, my long time, good friend and senior head nurse and who was soon to be promoted to supervisor, told me:

I have a good working relationship with most of the doctors of this department, including Dr. Vena. But, the conflict between the two administrators makes my working hours most unhappy. I hope the problem can be overcome."

The conflict however, was to remain a source of nurse discomfort as no one tried to remedy the problem. However, many staff had hopes that in the next three years things would be better because of the pending retirement of Dr. Vena.

THE SUPPORTIVES
Apart from providing treatment to cancer patients, the Radiological Department of Siam Hospital also provided material support to the patients. There were two sources of support provided, formal support, sponsored by the hospital and controlled by staff of that department; and non-formal support, sponsored by private persons who wanted to donate money for the betterment of cancer patients. This support was controlled by Mrs. Pranee, who told me that this money was only a very small amount and was given by the nurses in the hospital who wanted to make merit. She related how:

It started when one of my senior nurses came to me and told me that she wanted to tham bun [make merit] for her son who had cancer. She gave 500 baht a month for supporting needy cancer patients. Normally, I use the money for food, transportation, or other things that patients need. Most patients who came to ask for help from me are referred by my acquaintances.
... Normally, I would send patients to see the social worker first, but if they were rejected I would help them. Because there is not much money in the fund, I can only help them with a small amounts and sometimes it is not enough for their needs. At times when I run out of money, I ask for donations from my friends.

Patients however, rarely called on these funds as a source of monetary relief. The same patterns of behaviour in relation to the use of hospital or charitable resources that were so often seen throughout the course of this study, were also evident in the use of these donations. Although most patients did not know that this source was available and that it existed expressly for the very situations in which they would find themselves, those patients who did know, would surely not dare to ask. Some mentioned that they felt too shy, whilst others would say that it would mean a loss of face to accept such help. The few patients who were offered assistance, mentioned that they felt humiliated when confronted with this offer and the thought of having to accept such charity.
CHAPTER 8

LIFE IN THE THERAPEUTIC PLACE

The Therapeutic Task

In this chapter, an examination is conducted into the daily role of the treatment centre in providing the various types of therapeutic care for the cancer sufferer. As well, the consequences of those functions and the effects felt by the patients are also analysed so as to give a more explicit understanding of the patients experiences within the therapeutic environment.

At one level, the function of the Radiological Department as a treatment centre, could be defined as an institution which exists to serve the demand that some kind of cancer treatment, including that of radiotherapy and chemotherapy, be provided for those cancer patients in need of such treatment.

In order to understand the lived experiences of the cancer patients and to give a more credible account of those experiences, I found it necessary to understand all aspects of the treatment programme which could have an influence on those being studied. Therefore, it was felt that although the overall focus of this study was on the lived experiences of cancer patients in an institutional setting, the ways and the means by which the treating facilities went about effecting a treatment stratagem, could not be ignored.

In examining the impact of this institution on the patients, it was not simply a matter of studying the characteristics and traits of the staff and patients and the roles played out by them in their daily routines, but rather, the emphasis of the investigation was on the effect that the organizational relationships had on the lives of those within the therapeutic institution setting.

Becoming Patients

On referral to Siam Hospital, patients who were making their initial visit, were directed to the Out-Patient Department where they were obliged to undergo a re-examination and investigation by department doctors as part of a screening process prior to them being
referred to the specialists in each field as well as establishing an 'in house' diagnosis. The reason for this second investigation, was to confirm the diagnosis which was an important beginning to the outlining of a treatment plan.

The medical activity at the Out-Patient Department, was generally concerned with the diagnosis which was usually established by the recognition of symptomatology and confirmation of any previous diagnosis by specific tests as well as results of any previously conducted clinical examinations brought along by the patients. Some diagnoses were confirmed by means of microscopic examination of the living tissue and/or interpretation of X-ray films and/or radio-isotope scans.

The type of investigation largely depended on the considerations of the doctors, after which patients were informed that they would have to undergo certain examinations and investigations without any further consultation or explanation from the doctors other than, "It is necessary." At this point in their health-seeking endeavours, patients who came to Siam Hospital with expectations of completing the treatment programme in a rather short period of time were, sorely disappointed. As well, for most of the patients, it was also a time of confusion and through the absence of any real doctor/patient communication, their existed an inability to understand the process of investigation. Mr. Pratin expressed the patients feelings in stating:

...My doctor back home in Phetchabun had given me a letter to bring to Bangkok requesting that I receive radiation treatment. I was assured by him that if I came to this hospital and received that treatment promptly, I would have a one hundred per cent chance of being cured... So, I came here and presented the letter, but instead of commencing some form of treatment, as I had expected, I was given appointment times for a range of tests which took me about half a month to complete and which forced me to travel to and from my house four or five times to keep those appointments.

For most patients, the establishment of a diagnosis was completed at the Out-Patient Department. For some however, the induction procedure would involve a visit to another department for specialist consultation. And so, on the completion of all diagnostic and administrative aspects, patients were referred to the hospital's various treatment departments to commence the preliminary phases of their treatment.

Most Cancer Hostel patients were referred directly to the Radiological Department, although some were referred to other departments to undergo some form of treatment before being referred for radiation treatment. An example of this induction procedure was
seen in the case of Mr. Adoul, who on being diagnosed as having cancer of the tongue, was referred to the Surgical Department from the Out-Patient Department where he underwent surgery to remove the affected area of his tongue and after waiting for about a month, was referred back to Radiological Department to commence radiation treatment.

**Prescribing the Treatment**

The personnel who ran the treatment programme expected the patients to submit to all of the techniques and facilities of modern medical science employed within that programme and which the doctors would bring to bear upon the diagnosis in the treatment of their condition. As well, once the patients placed themselves into the programme, they were expected to co-operate fully with all staff concerned, thus requiring the patients to do everything they could to facilitate their recovery.

The cancer treatment provided by the Radiological Department included both radiation therapy and chemotherapy, with the majority of those receiving treatment at this department being out-patients, including those from Cancer Hostel with only one in ten being in-patients.

**RADIATION TECHNIQUE**

The two means of delivering radiation therapy employed by the the Radiological Department were teletherapy and brachytherapy, in which teletherapy makes use of a machine to deliver ionizing radiation from outside the body, whereas brachytherapy is a form of internal radiation therapy in which a radioactive source was placed within or close to the tissue to be treated. The radiation therapy facilities operating in this department, included, three machines for providing teletherapy and five bed units set up for use with afterloading applicator techniques, of which three were remote control units, for use in brachytherapy.

**Teletherapy**

In providing teletherapy (external beam radiation), where external radiation treatment was given with a machine or source being at some distance from target site, the Radiological Department operated three machines which ranged in capacity type from,
Kilovoltage, producing X-rays with minimal penetration; Megavoltage, which generated gamma rays from Cobalt-60; and Linear Energy Transfer radiation of electrons providing both high dose, deep penetration and low dose, superficial penetration.

**Brachytherapy**

Brachytherapy, the internal radiation treatment technique in which radioactive isotopes were used for surface, interstitial, or intracavitary application. The treatment objectives in using brachytherapy techniques, were to provide a high dose of radiation to be delivered to the tumour volume being treated and with a rapid fall off in radiation dose in adjacent normal tissues.

Although there are many types of brachytherapy applications that can be used to enhance the overall treatment effect in various cancers, only intracavitary implantations were selected to combine with teletherapy for use in treating the cervical cancer patients from Cancer Hostel. The Radiological Department employed three intracavitary techniques used in treating patients, these being, Intracavitary implantation of radium 226; Selectron HDR applicator using cobalt 60; and Selectron LDR applicator using Cesium 137.

Intracavitary implantation of radium has been used in the Radiological Department of Siam Hospital since 1973. Within this technique, the empty applicator was inserted into the patient's cavity in the applicator inserting room, after which the patient was then taken to the radiation treatment room where radium was loaded into the applicator. Radium was left in the intracavitary applicator for about 72 hours and then removed. This single insertion, intracavitary radium application, was not often used at the time of this study, as this treatment technique was time consuming as well as being less convenient than the other two techniques. It was however, to become the form of treatment for one patient when the Selectron LDR device became unserviceable.

At Siam Hospital, Selectron HDR and Selectron LDR remote controlled devices were the preferred means of providing intracavitary treatment, having a number of advantages over intracavitary implantation of radium. Of major benefit was that by presenting a larger radiation dose more quickly and accurately to the treatment site, and the reduced amount of time that the radioactive source was allowed to sit in the treatment area, meant a considerable reduction in the treatment time allowing a greater number of patients to be treated. As well, because the treatment devices were remote controlled, whereby a radioactive source was inserted, removed and stored at will, control over a hazardous substance was achieved with a greater degree of safety for staff members by minimizing
the threat of exposure to radiation. This was particularly so in cases requiring bedside care during the course of treatment as these machines allowed the radioactive source to be withdrawn from the patients and re-inserted after bedside care was completed.

In using Selectron HDR, cobalt 60 was left to sit in the applicator for about one hour before being withdrawn and was normally used as a multiple insertion regimen with patients usually undergoing four insertions and was used in combination with the normal daily teletherapy treatment. When using Selectron LDR, the insertion of Cesium 137 lasted sixteen hours, being normally used with patients requiring a single insertion and was also combined with their daily teletherapy treatment.

Radiation Treatment Prescription

The type and length of the course of treatment depended on the nature of the disease as well as the patients physical condition. A doctor from the Radiological Department explained:

The treatment of the squamous cell carcinoma of cervix stage 2 and stage 3 may be a combination of telecobalt therapy [teletherapy] and Selectron HDR or LDR using the remote control afterloading applicator [brachytherapy]. Those patients receive 4,000-5,000 rads from the telecobalt 60 during their course of treatment, with 200 rads given daily over a period of four to five weeks. During the telecobalt therapy, patients receive intracavitary treatment. This treatment is Selectron HDR or LDR, depending on the patients condition. If the patients are young and co-operative we prefer Selectron HDR. For the more elderly patients or for any patients who show signs of being unco-operative or that they were about to drop out from the programme, Selectron LDR is the preferred treatment.

Chemotherapy

Chemotherapy treatment was also available in the Radiological Department. Most chemotherapy given in this department was to enhance or assist radiation treatment. One of the doctors explained the reason for integrating the two treatments:

We combine chemotherapy treatment with radiation treatment in those cases where we want to achieve local and metastasis control. For example, radiation is given for local control of advanced or recurrent breast cancer, as well as head and neck cancer, whilst chemotherapy is used to deal with micro-metastases which are inevitably present but undetectable.
A number of considerations were faced by the doctors in determining whether or not to integrate these two treatments. Financial factors also played an important part and was invariably taken into account before deciding on a treatment plan. One of the doctors made this point clear:

The cytotoxic drugs are very expensive and we have only limited funds. Therefore, if the patients have financial difficulties and cannot afford those drugs, we would not normally prescribe chemotherapy to be used in conjunction with radiotherapy. However, in those cases where there is a high percentage chance of effecting a cure we will provide the drugs by using available funds.

During my time in Cancer Hostel, there were only three patients who received chemotherapy along with their radiotherapy treatment, Mr. Sangiem, who was suffering from hypopharyngeal cancer, Mr. Adoul, a patient with cancer of the tongue, and Mrs. Samran, a cervical cancer patient. In these three cases, only one was assessed as being entitled to receive free treatment, the costs being born by the special fund set aside for such exigencies. Of the other two cases, one was a serving government employee whilst the other was a retired, ex-government employee, whereby both were in a position to receive government reimbursements to defray any costs incurred whilst undergoing treatment. However, Mr. Adoul, complained that:

It will take at least a month for me to get the money back. I have to pay a week in advance on a weekly basis to cover my treatment here. It’s a lot of money really and I have none in reserve to cover any other eventuality. As it is, I have to borrow the money from my relatives or friends. I don’t know who my wife will approach this week in trying to borrow the money required for next weeks treatment. . . . It’s a very hard situation to be in.

Treatment Process

Before commencing treatment, all patients were required to go through a simulation process involving a series of steps that would assist in defining the radiation treatment target. During this process, the patient’s skin was marked with ink to indicate the area of treatment as well as to mark the co-ordinate points as a guide to the proper positioning of the machine. After completing the simulation process, patients were informed that their treatment would begin on the following day and allowed to leave and return to Cancer Hostel. Using those measurements and radiographs taken during simulation, the radiological physicists were able to make calculations that would enable the completion of
the radiation treatment plan. This planning helped to determine the final treatment prescription, which included the description of the treatment field or fields, total dose, daily dose fraction, and elapsed time.

Radiation treatments for patients who were undergoing teletherapy, were given on a daily basis, of a normal working week with the average course lasting four to five weeks. During each treatment period, most patients would spend approximately ten to fifteen minutes in the treatment rooms with only a few minutes of that time actually exposed to the radiation source, whilst the preceding time was spent in positioning the patients and the machine in readiness to treat each prescribed field. For example, cervical cancer patients generally required anterior and posterior field treatment, but only single field treatment was administered on any given day. Patients undergoing this form of treatment were set-up in either the supine position for anterior field or the prone position for posterior field with treatment alternating over consecutive treatment days. However, for some patients, the treatment prescription meant that they were to receive treatment from more than one machine or would require multiangled exposures or positional changes which would necessitate more preparation, and therefore, take a little longer to complete.

Most patients understood very little concerning the immediate physical effects of the treatment that they were about to undergo and although many of them would commence their treatment with expectations of feeling pain, heat, or at least some other form of unpleasant sensation, they really had no idea as to what to expect. Some patients however, had been reassured by their fellow patients, who had already commenced their course of treatment, that there was no pain or sensation of any kind during the treatment. Although this positive reassurance was true when referring to the actual radiation treatment itself, it was not entirely true when referring to the overall treatment procedure, as there would be a great deal of pain felt during the applicator insertion procedure.

Most patients revealed that it was the lack of information about the treatment procedures and the feeling of alienation within the treatment place which caused them to exaggerate their sense of fear. For example, the apprehension felt toward the treatment machines used for teletherapy, where its very large and formidable appearance completely overwhelmed some patients, with many saying that the machines had frightened them somewhat at the very outset of their treatment. Mrs. Loaun shared her experience:

It was really frightening for me at that time. That radiation machine is so big, I was afraid it would fall on me. The very first time I was really scared and I hardly breathed whilst I was receiving treatment. But it’s alright now, I have overcome my initial fear and I am a little more relaxed.
For cervical cancer patients who underwent brachytherapy, the treatment processes were more complex and required more preparation and treatment time. Two days prior to the commencement of intracavitary treatment and after they had received their normal daily radiation doses, those patients concerned would receive an appointment document from either the radiation technologist or from one of the domestic staff. There were no further treatment details given to them by staff members, other than to tell them:

This is your appointment form, read it and follow the instructions. Come here first and receive your daily treatment as usual, and then go and wait near the lift where you normally have lunch, a domestic worker will take you up to Ward 6 at about 1.00 pm and hand you over to a nurse in that ward.

The appointment document contained the name of the patient, the treatment date and details concerning their personal preparation, in which patients were asked to shampoo their hair and to ensure that their nails were cut short and kept as clean as possible before coming to the hospital for treatment. As well, a request that patients should bring items of personal hygiene for use during their overnight stay appeared on the document.

When the patients arrived at Ward 6 the day prior to treatment day, a nurse would assign them to their beds and request that they change into the hospital's bed clothes. In the afternoon, a nurse would conduct patient education on intracavitary treatment. This education was one of the nursing staff activities in the "Patient Health Education Programme" set by the hospital's Nursing Department and was aimed at giving the patients some knowledge about their disease and the form of treatment that they would undergo.

The education programme was designed for the patients who were admitted to Ward 6 for intracavitary treatment, but would also included Cancer Hostel patients as well as others receiving treatment on an out-patients basis. Once all patients with appointments had been admitted, a nurse would call them to gather around a wooden table used during these education sessions to instruct on the procedures that would be encountered during their treatment.

Patients who had previously experienced this type of treatment and who had been admitted for the second or subsequent treatment session, were excluded from the programme. The reason given for this was that only those patients who had no previous treatment experiences were eligible for the education programme. This was cited by one of the nurses involved in that programme, who added:
It would be boring for the patients who have already experienced radiation treatment and besides, it is not necessary. However, on some occasions I have asked them to join in the teaching hour and relate their experiences in support of the inexperienced patients. But, it has not been successful, as most of the patients were quiet and shy in talking about their experiences.

The information given by the nurse to those patients who were to undergo intracavitary treatment, included details on the patients' physical preparation, the procedure for the insertion of the applicator and the behaviour expected of them whilst the radiation source was being loaded. All of this information was contained in a 10 page flip chart which showed drawings, pictures, and word explanations and was used as an aid by the nurse to teach the patients, with each session lasting about fifteen minutes. In the meetings that I attended, patients showed little active response, and when asked by the nurse at the end of session "Does anyone have anything to ask?", most patients just shook their heads, there being usually no questions volunteered. However, after returning to their beds, they would invariably raise some questions among themselves. When asked why they hadn't brought those questions up with the nurse, most of them replied, "I didn't dare to ask" or "I didn't know what to ask."

Although patients had attended a teaching session and were instructed on the particular phases of the treatment procedure that they would be involved in, many would later show that they still did not understand. This became quite clear when following the patients who were to undergo intracavitary treatment and was particularly so in the case of Mrs. Loaun, who was to receive Selectron HDR and scheduled to undergo the first insertion. Mrs. Loaun was extremely wary of the impending treatment as was found on treatment day, when after the empty applicator had been inserted and whilst waiting for an X-ray confirmation of the position of the applicator, she spoke to me with teary eyes, saying:

I don't know what is going to happen to me next. I don't know if the raa [the Thai term for metal which can be used to refer to gold as well as other metals and in this case, when referring to the radio active source] has been inserted yet. Has it been inserted yet? It will hurt me again when the doctor puts the raa inside me"?

As can be seen from her confused line of questioning, Mrs. Loaun, as was the case for most rural people, did not have a word for a 'radioactive substance' and therefore, could not fully grasp what it was inside her or how it acted on her body. As well, she did not fully understand that she had already undergone the painful phase of the insertion
procedure. A later conversation with Mrs. Loaun would highlight her overall misconceptions of her intracavitary treatment and the effects that radiation would have on her. In this conversation, on the day prior to her completion of the treatment programme, she said:

I wanted to ask the doctor whether the disease had been cured or not, also whether or not the raa had been totally removed from my body. I was also very curious to find out what would happen if I went out to work in the rice field when it was raining and there was a lot of thunder and lightning. There was a woman in my village who went to work in the field after having raa treatment and still had some left inside her body and was hit by pha par [lightning strike]. I think that the lightning was attracted by the raa still inside her.

Mrs. Loaun’s understanding of her treatment, indicates that the information given by the nurse prior to the commencement of treatment, did little to enhance the patients’ overall knowledge concerning their treatment.

After the evening meal, the patients vulval area was shaved. A vaginal douche was given to remove any secretions and discharge, whilst an enema was given to reduce the chance of the patient having a bowel action while the radioactive sources were in place. All patients who were to undergo intracavitary treatment the following morning, were given an anti-anxiety drug to minimize stress and to ensure that they received adequate rest.

Treatment would begin very early in the morning and patients were roused from their sleep at about 5.00 am to undergo final physical preparations which would again include an enema and vaginal douche administered by a practical nurse, followed by a shower before they were taken to the applicator insertion room. The first patient was called into the treatment room at about 7.00 am, where the empty, hollow metal applicators, consisting of two vaginal ovoids and a uterine tube, were inserted and later loaded with the radioactive sources. The apparatus was held in place with a ribbon gauze flavine pack. The long ends of the applicators projected through the vulva so that afterloading could be carried out. A urinary catheter was also inserted to reduce the risk of the sources becoming dislodged by the patients when micturating.

The process of inserting the applicator took fifteen minute to one hour depending on the doctors skill as well as the patients anatomy. Patients who had the applicator inserted by an experienced doctor and who had a fairly capacious vaginal vault, would spend less time undergoing this process than those patients who had the device inserted by a junior or
inexperienced doctor. Any error in the insertion process would have to be rectified immediately and would of course, add to the time spent by the patient undergoing this process. Although not a common occurrence, evidence of one such error was found in the case of Mrs. Looan, where an 'unmatched pair' of vaginal ovoids were inserted. The mislocation of the clamping screw prevented the device from being tightened, thus forcing the doctor to remove the applicators and re-commence the process once again.

On completing the insertion process, patients were then taken to the X-ray/radiograph room and a film was taken to evaluate positioning of the applicator. Once the applicator had been inserted and assessed as being in the correct, pre-calculated position, patients were moved to the treatment room where the radioactive sources would be loaded. The amount of time that patients spent in the treatment room differed and would largely depend on the treatment prescription. On completion of treatment, the radioactive source was removed and patients were then placed under the observation of the nursing staff for one to two hours and then allowed to return to Cancer Hostel.

From my previous experience of working as a nurse in a similar setting at The Royal Marsden Hospital, London, the one major difference observed, was that here, no general anaesthesia was administered for the insertion of the applicator. For the Thai patient, this would be the cause of much pain and stress suffered during this procedure.

Patients with complications such as bleeding, infection, or severe pain were kept in Ward 6 for a further period of observation and treatment management, and usually after an overnight stay or when their condition had stabilized, were then allowed to rejoin the other patients.

There was no preparation for patients who were to undergo chemotherapy and those who had been scheduled for such treatment were called early, and after having completed their routine radiation treatment, patients were told by radiation technologists or assisting labourers to report to the nurse at the nursing treatment room. These nurses then checked the prescribed treatment, and if the treatment protocol dictated that the drugs were to be given by the intravenous direct push method, the house resident was called. Preparation and the administration of cytotoxic drug (single or compounds) was carried out by the house resident in the nursing treatment room. If the drugs were to be given through intravenous line, patients were told to go to the day treatment room in the Eastern wing of Ward 6 where the drug would be administered. At the day treatment room, venepuncture was done by one of the nurses and the doctor was called for the preparation and administration of those drugs.
In the past, cytotoxic drugs were prepared and administered by nurses of the Radiological Department. However, at the time of this field study those tasks were only carried out by the doctors. This change came into effect just prior to my entry into the field, after nurses who worked in those areas became increasingly concerned over the occupational hazards associated with the handling of cancer chemotherapeutic agents. As well, nurses were concerned over the illegal role they played in administering intravenous cytotoxic drugs and were well aware that it contravened hospital policies. Nurses were also concerned with patient safety as they had not been given adequate training in dealing with toxic reaction from such cytotoxic drugs.

In considering those hospital policies and to ensure optimal quality of care and patient safety, nurses rejected the responsibilities involved in the preparation and administration of cytotoxic drugs as being illegal and contrary to those policies. As well, there was no appropriate safety measures employed to minimize potential health hazards. The Director of Siam Hospital was left with no other option but to uphold the nurses decision and promulgated instructions that doctors were the only ones permitted to deliver intravenous chemotherapy. The stand made by nurses would lead to conflict between the head of the Radiological Department and the head of the Radiological Nursing Division.

Alternative Treatments

Although the use of an alternative treatment was not accepted by doctors of the Radiological Department, patients would continue to combine them with conventional treatment in what they saw as, an effort to gain the best of both worlds with one enhancing the effect of the other. The more popular alternative treatments were the taking of herbal medicines, ritual and religious practice, diet, and meditation and whilst they were quite openly practiced amongst themselves, most patients would keep these activities secret from the doctors and staff.

HERBAL MEDICINE

For fear that herbal medicines and radiation treatment were incompatible and that one would counter the therapeutic effect of the other, most patients refrained from using these potions during their course of treatment, although they were still regarded as the most popular alternative to combine with their conventional treatment.
Fellow patients and relatives played a crucial role in making this type of treatment accessible and with tales of miraculous cures, places where to purchase herbal medicine, samples, and home made remedies, being passed freely from one to another, patients actively prepared for using them on returning home, believing that "radiation treatment can cure cancer but not eradicate it."

RITUAL AND RELIGIOUS PRACTICE

Patients, in their efforts to rid themselves of disease would try most forms of alternative treatments with ritual and religious practice being the most popular means for those seeking safeguards and protection from any of the supernatural powers they associated with illness. Whilst for others, it was a way of distancing themselves from their illness problems. Being Thai, and having the same religious beliefs and values, it was sometimes difficult for me to understand some of the patients' behaviour. In dealing with patients who are, or profess to be Buddhist, I quite often came across daily life experiences and events that showed that they also held beliefs that are non Buddhist by definition and which were practiced without contradiction, either knowingly or unknowingly, along with accepted Buddhist ideals.

There has been much debate by eminent scholars on whether or not the Thai form of Buddhism is Animistic in nature, and therefore, it is not intended here to enter into that discussion. It is intended however, to present an authoritative view, in an attempt to provide a basic interpretation of what appears to be a duality of beliefs exhibited not only by those patients, but Thais in general.

Wijeyewardene, in his interpretations of certain forms of religious behaviour in Northern Thailand, specifically merit making, spirit mediums and local deities, discussed the place of Animism within a Thai Buddhist society. He drew on Mulder's views that:

... Buddhism remains animistic in the sense that merit making is generally understood as a mechanism to ensure safety and auspiciousness, institutionalized Buddhism becoming a power-house for individual and communal protection. Some people, though, are interested in the morality and wisdom of the Buddhist path and, especially in old age, may practice seriously. These people are no longer interested in the decha (power) dimension of existence. To most Thai, however, merit is a way to be safe in a world that is overlaid with power, and their use and understanding of Buddhism can best be characterized as 'Buddhist Animism'. (Wijeyewardene, 1986, p. 20)
It follows then, that Thai culture is influenced by both Buddhism and Animism which Wijeyewardene, in putting forward arguments to be discussed, noted, "Thai Buddhism has to do with power and wealth and status, but neither do the Thai need social scientists to bring this to their attention, nor is that all that Thai Buddhism is about." (Wijeyewardene, 1986, p. 15)

In summarizing the main points made in his essay, Wijeyewardene wrote, "The concern with karma and the pursuit of merit, we saw, was not merely inherent in popular Buddhism, but was somehow central to the ideology of spirit possession." (Wijeyewardene, 1986, p. 238)

It is important to consider this viewpoint in any of our attempts at finding a deeper understanding of why sick people, in this case, Thai cancer sufferers, react in ways that are not traditionally Buddhist and call on supernatural powers to help them overcome their illness.

**Diet**

Dieting behaviour was defined as taking special caution to avoid certain foods in attempting to control their conditions or the effects of treatment. For Thai people, food is not only thought of as providing nourishment and essential for sustaining life, but also as a source of sickness. Food that is generally bad for the health and the cause of sickness is referred to as ahaan salaeng (bad or poisoned food). There were a number of these foods which patients refrained from eating whilst they were undergoing treatment or had done so since becoming aware that they had cancer. Mrs. Wanna, a cervical cancer patient, listed eggs, salty fish and pickled foods as being ahaan salaeng and and were some of the foods she did not eat. She explained, "Eggs cause the ulcers in my cervix to become worse and also prevents them from healing." Mrs. Kesorn, in seeing Mr. Pratin drinking cold soft drink, remarked, "Look!, Pratin is drinking that icy cold drink, he doesn't seem concerned about it though. He should be more careful, it's not really good for him." On asking Mrs. Kesorn about this, she put forward the view that the coldness of the drink would inhibit the healing process of his neck.

**Meditation**

Many patients reported that they used meditation as a self-help method to assist in their coping with the pain of cancer illness as well as to help in overcoming the fear of death.
Others combined it with radiation treatment to reinforce its benefits and to help them to cope with the debilitating side effects. Mr. Pratin, one of those patients who regularly practiced meditation, told how he would prepare himself for his treatment sessions:

I meditate. I continue to meditate whilst I'm walking to the treatment room. I chant under my breath . . . *Sumphutho, Sumphutho, Sumphutho* [calling the Buddha's name]. I chant when they call me for treatment, I chant when I lay on the treatment table, I concentrate on saying over and over again, a wish for *sang saksit* [radiation, miraculous power]. [In this case, that radiation has the miraculous power to cure]. . . . It [cancer] cannot win over it.

Mrs. Nunn meditated as part of her normal daily routine, continuing this practice from her daily ritual as a Buddhist nun. She would always meditate at bedtimes, or whenever she felt the need in trying to cope with her suffering during particularly stressful times. As well, meditation was her way of coping with the pain and fear of death when left alone in the treatment room for sixteen hours of intracavitary treatment. She told how:

I was alone and very much afraid of death. It was sore, it was painful . . . I thought, I have to endure all this. Then I meditated. I concentrated on chanting *Phutho, Phutho* [calling the Buddha's name], I concentrated on *Loung Paw* [a respected, senior monk]. [This follows the Thai way of identifying themselves with a particular monk and who would commonly be referred to as "my monk"].

**Undergoing Treatment**

There were many negative factors which affected patients during their course of treatment and most would lead to their having to cope with varying degrees of fear, uncertainty, frustration, severe depression and in some cases, the first signs of anger. This of course, would have a direct bearing on the patients well-being, as well as having a detrimental effect on the overall success of the treatment.

**MECHANICAL BREAKDOWN**

The numbers assigned to receive radiation treatment would normally mean that the three teletherapy machines would be in constant daily use. However, during the first month of the observation period, one of those machines was out of action, which of course reduced the number of patients being treated on a daily basis. Delays caused by equipment failure
was a constant source of frustration for all concerned, there being at least another three occasions during my remaining five months in the field, where one of the remote control afterloading applicators would become unserviceable and withdrawn from providing radiation treatment.

During one of my many visits to the Radiological Department, I was on hand at the time when one of the radiation machines broke down and I was able to observe and note the responses of both the staff concerned with the operation of the machine, as well as the patients themselves.

The fact that a vital piece of radiotherapy equipment had broken down meant very little to the staff who seemed unfussed and went about the task of off-handedly informing the patients of the problem. One of the staff commented, "There is nothing we can do. When the machine broke down I went to inform the patients and told them to come back later, after which I went to help other staff members in a room nearby." In fact, the way in which the staff reacted struck me that it was a 'business as usual' situation, as if it was a common occurrence.

The breakdown of the radiotherapy equipment however, did bring out an important issue on safety concerning the over-exposure to radiation, which understandably, was of major concern for those who worked in that department and a cause of anxiety among the nursing staff. Those feelings of anxiety were expressed by one of the Ward 6 nursing staff, who outlined her views:

The remote control afterloading applicator here, breaks down quite often. It really worries me. Take yesterday as an example. When the patient asked for a bedpan I switched off the machine to draw the radioactive source back into the machine so that I could safely enter the room without fear of the radiation, but the applicator did not function properly. When I walked into the room, I checked the machine and found that some of the radioactive substance was left outside the machine and in the connector tube. I knew that I had a chance of being exposed to the radiation. I was very worried.

When listening to patient conversations and noting their responses to these equipment failures, two points of concern were continually raised when trying to discern how the delay in treatment was going to effect them. Firstly, the fear that the disease would progress during the period of non-treatment, and secondly, the time spent in waiting for
the problem to be rectified meant that the treatment period would have to be extended and would necessitate more time being spent away from their families. Understandably, the reaction of the patients was one of annoyance and they expressed this by complaining amongst themselves.

On one such occasion, one of the patients was showing visible signs of deep distress and a fellow patient, on noticing that I had joined them, approached me and pleaded for help. She asked, "Is there anything that you can do to help paa Lumpoo [paa, in the language of Thai kinship, is used to express a non-kin relationship in which a friend is referred to as an elder sister]. Of course, to accept the responsibility of intervening on behalf of Mrs. Lumpoo would be to relinquish the position of remaining an impartial observer.

The patients were not alone in their feelings of distress and annoyance at the situation that had developed through the continual delays in treatment. It was for me as well, during these times of deep distress and suffering, that feelings of pity, anger and frustration would almost engulf me at not being able to step out from the role of researcher in order to render assistance in the nursing role.

Mrs. Lumpoo had put up with her worsening condition and the delays in treatment for about four weeks although on numerous occasions I had suggested that she should see the doctor to raise the question concerning her treatment. She was obviously afraid to do this and did not know the process of how to go about seeking that help and would only ask the treatment room staff if the machine was back into service. This situation continued until I could not sit back any longer. The physical condition of Mrs. Lumpoo was deteriorating noticeably, and so, I decided to intervene by taking her to see the doctor.

My previous contacts with Mrs. Lumpoo would quite often see her confide in me and tell of her gravest fears, letting her emotions run free when talking of the situation in which she found herself. On this occasion however, it was quite noticeable from her behaviour that she was deeply upset. She was no longer the funny one in the group, no longer cracking the quick joke or giggling with the other patients over things they thought humorous. She had moved a little away from her group and laid down on a bench and placing her forearm over her brow, stared at nothing in particular. She was obviously most depressed and when drawn into a conversation, she began by mentioning that, "I am the unlucky one who has no treatment, not like all the others, they have their treatment." Later, when asked about the effect that the delay in treatment had on her, she replied:

I want to get better. I want to be cured. It is really painful and it's hot. I'm afraid that the ulcer will worsen until where it cannot be cured. I have a lot of
bleeding at the moment. I can't bear it, I can't bear it any longer. My heart is in a turmoil. . . . Last Friday, the radiological technician told me to go home and come back again on Monday. How can I do that? I would only get half way home and then have to turn around and come back here again. If I go home and then come back and the machine still doesn't work, what can I do next? If I want to go to another place for treatment, what place is there for me to go? If I do go, how can my son find me? Where can I get the money if that place asks for me to pay for the treatment?

Whilst Mrs. Lumpoo waited at Cancer Hostel, Mrs. Sar was one of those who returned home. She had travelled the 800 kilometres to her village and returned to the hospital on three occasions to enquire of the status of the treating equipment. Because she lived far from the hospital, the round trip home would take two days, and her travel experiences had left her exhausted. As well, there was the expense incurred in that travel, something that was not originally part of her budget. Mrs. Sar would later disclose, that one of the reasons for her returning home was because she worried about her father, who at that time was in the hospital in her home town.

In my early participation with Cancer Hostel patients, it was discovered that one of the patients had elected to discontinue any further treatment, his case being indicative of the frustration felt by the patients, as well as being an extreme example of the effects that equipment failure had on patients behaviour. Mr. Dang, the patient involved in this situation, had been undergoing treatment for soft tissue sarcoma and had been part of the treatment programme before returning home for one week after a similar equipment failure. He later returned to enquire as to his chances of continuing with his treatment, only to find the machine was still out of action. After spending further time waiting at Cancer Hostel and turning up at the treatment centre for a number of days in the hope that he would be able to continue his treatment, he returned home in disgust. This patient never returned for any further treatment and it appeared to be, as expressed by Mrs. Lumpoo, who had been receiving treatment at the same time, "For sure, he won't come back. He's given up."

COMMUNICATION BREAKDOWN

Some patients did not agree to undergo treatment in any shape or form let alone express agreement to having a plan drawn up covering a proposed treatment schedule. But rather, by their silence or their failure to respond to the broad proposals on the treatment of their illness, saw the formulation of a detailed treatment plan initiated by those doctors who assumed that the non committal attitude of the patient signalled their acceptance to be part of the programme. There was no such procedure in place whereby the doctors could gain
informed-consent from those patients about to undergo, which for most of them, was a rather harrowing form of treatment.

The treatment plan in itself, was well written up in the patient's file and would include such information as the type and source of radiation equipment which would generate the treatment, as well as the dose and the length of the treatment. There was however, very little information concerning the treatment being communicated to the patients.

This lack of even a rudimentary awareness of what the treatment plan entailed was evident in the daily discussions between the patients, where the common questions asked were, "Do you know how long the course of radiation treatment is that I have to undergo?" and "The doctor didn't tell me anything, he only told me that I had a chance to be cured. Do you know whether I have to undergo intracavitary treatment?"

When it came time for the doctor to inform the patient of the treatment, most were simply told that their treatment would be radiotherapy and that the length of the treatment course would be about one to one and a half months. There was no explanation about how the treatment worked or the symptoms for which radiotherapy could be induced. However, the doctors usually gave patients some degree of support and reassurance about the effectiveness of the treatment in telling them, "Don't worry it will be alright, your disease will be cured by the radiation."

Information on any additional treatment such as chemotherapy or intracavitary treatment would be communicated to those patients who were later to undergo that treatment, with some patients being told a number of days prior to treatment, whilst others were informed on the very day that the treatment was to be carried out. As well, some patients were not informed about their treatment at all. As Mrs. McInten said:

One day I was called early for treatment. Lek, [a labourer, who in treatment hours helped the staff in the general running of the treatment activity] then gave me a pathological request form and asked me to go to the pathological department for blood and urine tests. At the time, I didn't know the reason for all this activity, and even when I gave the results of the tests to her, she didn't say anything to me. When I asked a fellow patient about it, she told me that it was normal for the patient who was going to have a intracavitary treatment. I said, I was not sure, because my doctor hadn't told me of anything. It was true though, as two days later I had intracavitary treatment.

It was common for the doctors of the Radiological Department, in volunteering information to the patients concerning their treatment, to include very little detail of what
that treatment really entailed. As well, in dealing with the patients' questions about their treatment plans, the doctors would prefer to simply ignore any such request and give no further information.

In defense of these actions, the doctors would put forward their views that, in explaining the treatment plans in any great detail would serve no purpose, other than to confuse the patients even further in an already confusing time for them. But even more importantly, to introduce details on such things as 'how the treatment works' or 'the side effects associated with that treatment', would only bring worry and fear at a time when patients were most likely to drop out from the programme.

This belief was supported by a story recounted to me by Dr. Vena, the department head, during a conversation at the time when I was requesting permission to conduct part of my field study in the treatment centre. She related how:

On one occasion, many patients dropped out from the radiotherapy programme after volunteering to complete a research questionnaire as part of a research study conducted by the masters degree nursing students. I believe that some of the questions led the patients into misunderstanding the effects of the treatment. Here is an example of one of the questions asked, Do you have any of the following signs or symptoms after receiving radiation therapy: a. Hair loss; b. Dysuria; c. Bleeding per rectum; and d. Anorexia? I feel that these kind of questions lead the patients to think that they will develop one of those symptoms and that they would undergo physical suffering. The result from all this was that many patients dropped out of the treatment programme. The real tragedy however, was for the patients who ran away from the treatment, as there were many cases where the disease was in an early stage and could be cured by the radiation treatment.

Most doctors were aware of the patients negative attitude toward radiation therapy. Dr Rord, one of the senior staff of the department explained:

The negative attitude exhibited by the patients toward radiation therapy can be shown to be a consequence of the outcome of using radiation treatment palliation of symptoms in terminal cases. In the past, we started to use radiation treatment to control symptoms in advanced cases. Although it worked in terms of being an effective symptom control, most of the patients soon died. We know that the patients did not die from the radiation treatment, but in the eyes of the general public, the death of those patients has already been tied to the radiation treatment. The public believes that radiation therapy is not effective in fighting cancer, and in fact, it is the cause of death in cases in which it is the prescribed treatment. It is very difficult to change the attitude of people, especially those from the rural areas. Now, we hope that with the
success rate in early stage cases will show up and help the public have a better attitude toward radiation treatment.

There were some doctors who saw the treatment management of the patients as taking priority of tasks within their job as 'healer' in the Radiological Department. To them, this meant that as well as prescribing the treatment, they were also to work out and allocate the hospital's facilities that were available to the patients. On the other hand, the doctors' contact with the patients in relation to the passing on of any information concerning their treatment was treated as a low priority task.

An example of this was when, on one occasion, Mrs. Kesorn and I were sitting about one metre away from the desk of Dr. Nit and could see him going over the patient history file with Mrs. Mai (a newcomer at that time). On completion of the pre-treatment documentation, Dr Nit said to Mrs. Mai, "You will receive radiation treatment for about one month." He offered no other explanation and made no attempt to communicate further on the subject of treatment for Mrs. Mai. He then asked, "Oh! you live in Phetchabun, do you have any place to stay in Bangkok?" Mrs. Mai shook her head and in a very soft voice replied, "*mai* [No]." "*Mai pen rai* [It doesn't matter]", Dr. Nit retorted, "I have a place for you to stay. We will send you to see the social worker later, she will organize things for you to stay in the house which is free of charge." The doctor then busied himself in going over the patients file.

Whilst documenting the treatment plan in Mrs. Mai's file, Dr. Nit struck up a conversation with the practical nurse who stood nearby. He asked, "Do you know anything about the radiation machine in Room B and whether it has been fixed"? The nurse replied, "It was fixed yesterday, it should be OK".

The doctor continued to make a few more notes into the file, then turned to Mrs. Mai and said, "Now, you go to X-Ray first. The practical nurse here will tell you what to do." The patient said nothing, but simply *wai* the doctor and followed the practical nurse out of the room.

Observations made during the conduct of the Tumour Clinic brought out another example of how the information concerning treatment, was not passed on to the patient.
The Tumour Clinic was conducted twice weekly in the afternoon of the selected days and was run by the Radiological Department. This clinic provided an opportunity for the doctors from that department to consult in open discussion with the specialists in various fields from the other departments of Siam Hospital. The objective of this clinic, in forming an advisory panel from those select medical professionals, was to make up the treatment plans in cases where patients had not responded to prescribed treatment. Although this panel had no fixed membership, it would normally include specialist representation from the Surgical, Pathological, Gynaecological, and Haematological departments of Siam Hospital.

Mr. Prasert kept his appointment to be part of the clinics activity at 1.00 pm and waited outside the room for about one hour whilst another patient participated in the informal enquiry. Mr. Prasert began his session with the clinic when he was called into the room by a house resident doctor and was asked to sit on a chair in the middle of the room facing the specialists.

Normally, there were three to four specialists, three house resident doctors and three staff officials from Siam Hospital, all being positioned in a semi-circle, facing the patient. On some occasions, the medical students or the nursing students from the university attached to Siam Hospital, were allowed to attended the clinic. These observers would sit behind the specialists and take no formal part, although they were allowed to ask questions during the activity.

After Mr. Prasert was seated, one of the resident doctors read a report which included a summary of the diagnosis, the treatment, and problems associated with the treatment, which for Mr. Prasert was, in part, "... in nearing completion of the prescribed treatment period, the swelling associated with a tumour of the patients neck, has not responded to the treatment." The panel members were then invited to air their views and comment on the case.

The panel’s participation began with the normal questions and answers as well as suggestions concerning Mr. Prasert’s case. The doctors contributed most to the discussions and it quickly became a meeting dominated by those medical professionals. As well, because of the medical parlance used in referring to the patient’s treatment history and future curative options available, the communication process remained confined to that select group.
This meant, that for others in attendance, it was either a case of not being asked to contribute, or as it was for Mr. Prasert, not understanding what was being discussed or how any of the conclusions being drawn would influence future treatment.

The clinic concluded with the surgical specialist present, agreeing to operate on the mass, but only after knowing the result of biopsy. The suggestion of what should happen in Mr. Prasert’s case was duly noted by the resident in the patient’s file as:

Surgical Suggestion: The removal of the right neck node can be done, with a request that it only be attempted on knowing the result of the mass biopsy.
Plan: 1. Send OPD EENT for Bx of right tonsil; and
2. Attend OPD surgical after receiving result.

On completing the notation into the patient’s file, the house resident called on Mr. Prasert to leave the room along with simple instructions for him to report to EENT of the Out-Patient Department the following day, this being the only information given to Mr. Prasert.

After accompanying the patient from the room, I asked Mr. Prasert what his understanding was from what was discussed during his clinic appearance. Mr. Prasert looked worried as he answered:

I could not understand what was being said by the doctors because I didn’t understand the language they used when talking about my case. I only know what I was told by the doctor before I left the room, that I have to report to EENT tomorrow. I don’t know why I have to go to there.

It can be seen from this illustration, that although the treatment plan had been well drawn up, the communication to the patient of what had been planned for him was not as clear as shown in the patient’s file.

Some doctors, instead of spending time in explaining the treatment plan, concentrated their efforts on such things as ensuring that the patients were in a position to purchase the treatment drugs, either by direct payment from the patients own resources or through the manipulation of the various monetary assistance funds, and would therefore be able to
continue receiving the prescribed treatment. This was the case for Mr. Adoul, who on first visiting Dr. Pat, after having received radiation treatment for one week, was told that he would also have to receive chemotherapy once a week. Mr. Adoul continued:

He didn't tell me anything more about my treatment, he only asked me about the money for the drugs. When I told him that I didn't have enough money, he just looked at me and told me that he would borrow the drugs for me at that time, and asked me to return later. He then took me to another room where he told one of the female staff to organize getting drugs for me.

There were many opportunities during their course of treatment for the patients to see the doctor. These opportunities were either when patients were called in to undergo routine, periodic checks or when patients had asked for an appointment to visit the doctor. In these cases, patients were more likely to see the doctor as part of normal routine, than it was for them to request to see the doctor. It was indeed, only on rare occasions that patients would ask to see doctor for consultation about their symptoms. Patients were usually seen and examined by doctor on a weekly basis as part of a status check which served to monitor the progress of treatment or to assess any reaction to treatment. As well, patients also met with the doctor when they were undergoing the various forms of treatment.

The point being made here, is that although there were ample opportunities for patient and doctor to meet and discuss any illness, ailment, or problems associated with treatment in general, the lack of a viable means for opening any form of communication dialogue, prevented any meaningful information passing between both parties. Whilst this is not meant as a critical exposé of the communication conditions existing between doctors and patients, it does highlight the fact that excellent opportunities to improve the knowledge and understanding of both parties, normally went begging. As well, by simply providing a venue and allotting precious time as an opportunity to meet, does not necessarily guarantee the success of any communication. The failure of any communication in these cases rests squarely with both doctors and patients. The doctors, for their attitude in thinking that patients only come to see them for the relief of pain, as well as for being brusque and impersonal in their rather brief encounters. The patients, for their inability to overcome feelings associated with krueng jai and "not daring to ask."
A case that bears-out these observations was that of Mrs. Utorn, who on requesting to see the doctor over abdominal pains, could not bring herself to ask the doctor as to the cause of the pain, but rather, accepted a prescription for antacid tablets. Mrs. Utorn's failure to ask the doctor as to why she was suffering those pains, was because she would never "dare to ask", as well as her belief that the doctor would volunteer that information without her having to ask. When talking with Mrs. Utorn after her visit, she invited me to look at her prescription form and asked could I tell her what had been written by the doctor. The following conversation took place after being handed the form to read:

Mrs. Utorn: What did the doctor write on this form?
R: The doctor has prescribed gelueil and baralgan for you.
Mrs. Utorn: Oh!, I won't buy those drugs. I have a good supply with me. It would be a waste of money.
R: Then why did you go to see the doctor?
Mrs. Utorn: I went to see the doctor because I wanted to know the cause of my symptom. I wanted to know why I have these abdominal pains. Why I feel sick and have lost my appetite.
R: Why didn't you ask the doctor?
Mrs. Utorn: I didn't dare to ask. Really, he should tell me the cause of my symptoms.

This Thai trait of "not daring to ask" was typical of the patients attitude adopted when confronted with problems of this nature and stems back to Thai social values of kren g jai and can be found within all levels of Thai social structure and is not just to be found among the rural people. The social value of kren g jai (self effacement, humbleness, extreme consideration for, respectfulness, and so on), toward a superior or even within one's own social class, is discussed later in this chapter.

This then, leads to a situation in which much of the communication between patients and doctors was based on a one way communication model where messages were created by doctors and other staff and sent to the patients. Being a one way communication model, allowed doctors to dominate the doctor-patient relationship and was fueled by patients attitude of not wishing to impose upon the doctors superior office or to upset the status quo of 'superior-subordinate'. All this can be seen as directly attributing to a breakdown in all but the most rudimentary forms of communication.
THE UNCERTAINTY

For most Cancer Hostel patients, uncertainty was an experience that was ever present in their every-day life whilst in the institutional setting. This uncertainty was influenced by illness and treatment-related events, as well as the hospital staff.

Cancer Hostel patients showed a different attitude toward radiation treatment than that shown by their doctors. Many patients were not sure that radiation treatment, which doctors, as part of the modern medical system seemed to have pinned their curative hopes on, would in fact cure their illness. On the other hand, and more importantly for them, most patients knew that radiation treatment could be a threat to their life. Whilst they were at Siam Hospital, many patients expected that the doctor would be helpful toward them in their efforts to more fully understand their treatment, but with the communication system in the setting as it was, that information was not forthcoming.

Most of the patients therefore, commenced their treatment with some degree of hesitancy and a feeling of uncertainty, with all patients later expressing a dissatisfaction with the limited amount of knowledge they had concerning the treatment programme which they were about to undertake. The amount of information being passed on to them was negligible with many of the patients being critical of the doctors for not imparting, what they considered to be, important news of events which directly affected them.

As well, many were displeased at not being given an opportunity by their doctor during their brief consultation encounters, to ask for information about their upcoming treatment. Mrs. Mai related to one such experience:

That male doctor didn’t give me time to ask any questions. After my examination, he told me that I would have to stay to undergo daily radiation treatment. When I told him that I had no place to stay, he called for one of the nurses to take me to see the social worker and when I was just about to ask him more about the treatment, he called a new patient into the examination room. Really, he was in a hurry at the time. He never let me open my mouth to ask him anything. So, at the moment, I don’t know how long I have to be here.

There were some patients however, who did not complain or attempt to question the doctor at any time during their treatment period. To quote the term used by Mrs. Chum, they played the role of "the good patient." In explaining her idea, Mrs. Chum related how:
Good patients shouldn't be fussy. It's not a good thing to ask the doctor about things. Whatever the doctor asks you to do and whenever he says something to us, we should do as we are bid. He must know what is best for us and we should show by our actions that we appreciate that.

Most of the patients exhibited the same trust and respect toward the doctors as shown by "the good patient." As well, many patients adopted an attitude of kreng jai in accepting the doctors word. They did not dare to ask any questions and allowed the doctor to control them throughout the course of the treatment programme. Mrs. Loaun told how:

I wanted to know the answer to many things, such as, whether or not I had to undergo intracavitary treatment and that if I did, what type of treatment would be involved. Would the treatment be four, two hour sessions or a one time treatment over one day and night. However, I didn't dare to ask. I felt kreng jai when I was with the doctor [Mrs Loaun considered the feelings of the doctor as being more important than her own], because every time that I kept my appointment with her [the doctor] I saw many patients outside in the queue, waiting to see her.

Many patients harboured feelings of suspicion over the benefits of the treatment. As well, they were quite mindful of the harmful effects that the treatment could have on them. As will be shown further, these feelings of uncertainty were to stay with them throughout the course of their treatment.

THE CONFUSION

There were many patients whose treatment programmes were changed by the doctors. This was particularly so for patients who had undergone treatment for some period of time and where the doctors had evaluated their response to that treatment. For some patients, the doctor would simply adjust the treatment for a better therapeutic effect, whilst other patients were prescribed additional treatments which were to be administered in conjunction with that initially prescribed. As well, there were occasions when patients were removed from the original programme and put on to a different type of treatment altogether.
The changes in the patients treatment programme were well documented and written into the patients files to ensure the broadest possible dissemination amongst staff members of changes to patients treatment regimen. The patients however, were told only that they had to undergo a different type of treatment as well as the place where they were to report to receive that treatment.

Some patients, on being informed of a change to their treatment, were presented with a somewhat confusing situation. An example of just how confusing it was for the patients is brought out in the case of Mrs. Sar, a breast cancer patient who was referred to Siam Hospital for medical treatment after having a breast removed at a provincial hospital.

Mrs. Sar began her treatment at Room B and received radiotherapy from that room for three weeks. The doctor then told her that she would have to report to Room C to undergo a different type of radiation treatment which was to commence that same day.

The following day, whilst talking with me on her way to receive her second treatment, Mrs. Sar was called over by staff from Room B and asked why she hadn't reported there for treatment on the previous day. Mrs. Sar informed them that she didn't know that she had to. The Room B staff then told her that her treatment there was not yet finished and that she was to wait there for treatment.

Whilst I was sitting with Mrs. Sar outside Room B, staff from Room C walked past and told her that she had to go for radiation treatment at Room C first. Whilst walking to Room C, a staff member from Room B again asked her to wait. Mrs. Sar did not reply, however her face showed signs of puzzlement as she walked back and sat on the same seat as before. At this juncture, I thought it prudent to inform the staff of Room B that Mrs. Sar had been told that she had to receive treatment from Room C before reporting to Room B. The Room B staff then allowed her to go to Room C.

Throughout all this, the patient showed no sign of anger toward the staff of both treatment rooms, but rather, showed only signs of confusion. It was with feelings of anger and frustration which prompted me to write at the time:

Today, I felt anger over the way that the patient [Mrs. Sar] was treated. I also have a feeling of anger when I think of the way the patient tended to accept everything without once asking for some clear directions. My feelings want me to cry out "What is going on here". After speaking with the staff, I told
the patient. "Today, when you go for your treatment, you must ask the staff exactly what it is that they want you to do". But really, I know that she will not do as I ask.

Patients who entered the treatment programme, did so because they needed to be cured of their illness. They were told what to do and they did it, without questioning. Mrs. Sar, like most patients that I observed, did nothing in the way of asking the staff of both treatment rooms for some clear instructions as to exactly where and when she should report for treatment.

Two days later, when I was sitting and talking with Mrs. Sar, she began to show the first signs of anger in expressing her annoyance over the change to her treatment:

I don’t know anything about the new treatment programme. To change the treatment now means, as I see it, that I have to have radiation treatment twenty five more times. It’s like starting the journey from Phetchaburi to Bangkok all over again. At the moment, I cry every night, I don’t know when I can go home. I want to go, but my son won’t let me go back. He said that I should wait until I have completed the treatment because he has no money for me to travel.

THE INACTION

Although patients were scheduled for only five to ten minutes radiation treatment per day during a normal working week, they were compelled to remain in the confines of the treatment centre for up to five or seven hours. Because of the current system of 'patient management' employed by the treatment centre, patients were forced to endure days of complete idleness in waiting to be called for their treatment session. Remembering that these patients were mostly rural folk and accustomed to hard work with little time to spend in just lolling around, it would make these days of inactivity even more unpalatable.

There was no roster to show the patients the approximate time that they could be called for treatment. As a result, patients had to contend with a 'luck of the draw' situation in facing their daily treatment ritual. Knowing that they could be called for from the time of their arrival to the end of the days treatment period, meant either a minimum wait of a few minutes or a wait of up to five or seven hours.

It is not surprising then, that a constant cause of complaint from Cancer Hostel patients concerned the amount of time spent in waiting, which to them was an extremely boring
time with only the wondering as to when it would be their turn for treatment to occupy their thoughts.

All patients were told on arrival at the waiting area that they were to place their hospital identification card in a box provided near the entrance to the treatment rooms. This was to let the staff know which patients had turned up for treatment as well as giving them an idea of what order the patients should be called for treatment.

For the patients, it was logical and fair to assume, that those who came first would be called first. From the observations made however, this was surely not the case as Cancer Hostel patients would see other patients who had submitted their identification cards after them, called in for treatment in front of them. This point was keenly noticed by Cancer Hostel patients and was of some annoyance to them.

A department radiotherapist, whose daily tasks also involved her with the selection and allocation of patients to the necessary treatment facility, gave the following account concerning this situation:

There is no set treatment schedule, since the patients do not always arrive at the allocated time. As well, there is always a large number of patients to be treated with the limited facilities that we have, which in turn causes the long delays. The time allotted for a patient to receive treatment depends on the time that they arrive at the treatment room. We try to place the patients to receive their treatment as quickly as possible. Of course, all the patients want to receive their treatment first. We give priority to in-patients as we don't want to interfere with the ward routine. For the rest of the patients, we try to alternate between out-patients and those from Cancer Hostel. We know that Cancer Hostel patients come early, but really, they have nothing else to do and they have to wait for transportation anyway. For me, it does not matter if they receive their treatment early or late.

Of course, the hostel patients saw things quite differently and were rightfully concerned over how the prolonged periods of waiting affected them. They spoke of their worries over what they considered to be a daily ordeal:
Mrs. Von:

Sitting for so long makes me tired, but if we could receive our treatment early, we could go to rest or lay down in the waiting area near the car park or some other area in the building.

Mr. Pratin:

Having to wait for such a long time causes me to worry. I worry that if I leave the area, even for a minute, I will miss the call for my turn for treatment. We can't do anything, we can't leave the area, even to go to the toilet or for a drink of water, we could miss our turn.

Mrs. Samran:

We worry at being one of the last to be called as this will cause a delay for our group in returning to Cancer Hostel. I feel kreng jai when I know that the other patients are waiting for me.

And so, whilst waiting to be called, most patients sat quietly, with little noticeable movement or conversation among the various groups. This lack of the normal brisk chatter was most noticeable among the female patients. Now, intent on not missing the slightest sign of activity, they sat as if transfixed for long periods in the same position, their eyes on the door used by the staff, waiting for their name to be called. Others, having completed their treatment sat waiting for the transport to take them back to Cancer Hostel.

THE ISOLATION

In order to reduce the risk of exposure to radiation, the 'golden rule' of 'Time spent in the treatment room should be minimized and distance maximized', was set for the staff to follow once the radioactive source had been loaded into the applicator. This procedure was adopted to provide a 'safety in caring' environment. Patients undergoing intracavitary treatment were confined to the radiation treatment rooms at one end of the ward and separated from the rest of the patients with the period of time spent in isolation depending on the radiation treatment source employed and could vary from one to seventy two hours. Although the patients knew that the limited contact between them and
others was enforced for safety reasons, they still had a deep fear of the isolation, especially in cases of prolonged periods of treatment. This fear was shown in the case of Mrs. Nunn who underwent sixteen hours of Selectron LDR treatment. Mrs. Nunn recalled the feelings she had at that time:

I thought that I was dead. They put me into a room where there were three beds, but there was no one else in the other beds. I was left alone and no one came into the room, not even the nurses or the doctor would walk into that room. It was like lying in a coffin, surrounded by four walls. I was really scared.

This fear of isolation was not only felt by patients whilst actually undergoing treatment, as most patients also encountered experiences of being isolated from their families, not caused through any rejection by their family, but rather through the difficulty in communicating with them. Being away from their families and not hearing any news from them was the cause of great anxiety for most patients, and it was considered lucky by them to receive a visit from their loved ones once in their four to six week stay.

In rural Thailand, there is little in the way of the communication network facilities that are found in the larger urban areas throughout the country, and as most patients came from rural areas, they found that retaining contact with their families to be extremely difficult. For most patients, there were no convenient means of transportation, such as road, rail and air, and as telephone, or any other form of electronic communication was non-existent, direct person-to-person contact was the only possible way to get news in or out of their communities. Moreover, the inability of most patients and their families to read and write was another problem that had to be faced and precluded the use of the postal services, the only communication mode left open to them.

For a variety of other reasons, patients did not use this service, mainly because they did not know where to post any correspondence to, as mail was not delivered to their village and they were also put off by previous experiences with this service. To make use of this service, recipients would have to travel to the nearest mail centre, usually to find that their mail had been opened as well as having to have the contents of their mail read to them by one of the postal employees.
THE HARMFULNESS

During the treatment programme, many patients felt that they were harmed by the treatment procedure or the side effects of the treatment, and for some patients, a combination of the two.

For those women patients suffering from cervical cancer and who were undergoing intracavitary treatment, it was the most physically traumatic experience that they had ever encountered. Some patients stated, that the insertion of the applicator was an almost unbearable event, whilst others mentioned that the effort in trying to remain still in the lying position (to prevent a change in the position of the applicator) for the duration of the treatment, was by far the worst part of a particularly unpleasant time.

Many of these patients would claim that the greatest amount of pain was caused by the doctors when inserting the applicator into their vaginal cavity. In their eyes, the actions of the doctors (during those times when manipulating the treatment device) were seen as being rather rough and not what one would expect of professionals who were charged with caring for the sick. This was also a regular topic of discussion among the patients and on a number of occasions, I became involved in discussions where the patients would recall their painful treatment experiences. On one such occasion, when visiting the patients in one of their rooms at Cancer Hostel, I was hailed by Mrs. Nunn, who at that time was talking with Mrs. Sai, and beckoned me to join in their conversation. Mrs. Nunn told me that Mrs. Sai had not gone to have dinner because she was suffering from the effects of the treatment. When I asked Mrs. Sai about her treatment ordeal, she answered rather angrily:

I was in great pain and I could hardly walk. It was really sore all over my bottom. I have never been sore like this before, not until two days ago when the doctor inserted the applicator. . . . It was not his [the doctors] body, he didn't care how much pain there was. When he was putting the packing gauze into my vagina, he just kept on poking it in. He kept poking it in until I cried out that I was in pain, but he didn't stop, he only said that it had to be done. I am glad that it's all over. If I have to go through that another three more times like the other patients, I don't know if I could stand it.

The patients, in their discussions would compare the techniques of the various doctors and it was not long before it was known which of them would display care and consideration in the handling of the treatment devices, and most importantly, care when manipulating those devices into their bodies. At the same time, the patients got to know rather quickly who the rough ones were.
An example of just how observant the patients were in this respect, was recalled by Mrs. Kesorn, who although having endured an extremely painful experience, was still aware of the attitudes displayed by the treating doctors. She recalled how:

On Tuesday last week, I went to have intracavitary treatment. It was very painful. I knew that she [the doctor] was in a hurry to go to a conference as she was talking with the nurse and telling her about it. While she was talking she poked the packing gauze in very hard and quick. . . . But this week, it was a male doctor who inserted the instrument into me. He was very gentle, it did not hurt as it had the week before. I saw him this morning as he walked past me on his way to the treatment room, and he smiled at me.

It was obvious from the way Mrs. Kesorn spoke about the male doctor and of his caring ways, that she was appreciative of someone who took the time to be gentle and kind and who would, by adopting this caring attitude, endeavour to limit the amount of pain caused.

Not all the patients however, blamed the doctors directly, although from their accounts of their treatment experiences it was quite obvious that they held the doctors accountable for the pain they felt after their treatment sessions. Mrs. Loaun told how:

Inserting the applicator was very painful. She [the doctor] inserted the wrong applicator into me, they [doctor and nurse] had a big laugh over the doctor selecting the wrong applicator. The one that was meant for paa Kesorn was inserted into me and it was only after they had difficulty in fitting the instrument together that they realized it was the wrong one. It was very painful when the doctor removed it, so painful that my eyes began to water and my nose ran. Later, the pain was so intense that I felt that I would not be able to walk and would have to crawl. . . . Because of the pain that I experienced at that time, I thought of giving up the treatment and running away.

Some patients, although not experiencing problems during the applicator insertion procedure, would find that to remain still in the one position for long periods of time in order to keep the applicator in the correct position, was a very intense period as well as being, by far the most harrowing part of the treatment. These patients also mentioned that they could feel the pain gradually increase once the applicator had been withdrawn.
For them, the distension of the packing gauze would create a feeling as if the muscle at the vaginal area would split and tear away. As well, patients who had to lay in the one position for long periods, found that by the end of the treatment they had no feeling in their legs.

All patients suffered from the side effects of radiation therapy, including fatigue; malaise; mucositis; esophagitis; diarrhoea; cystitis; vaginitis; passage of mucus and blood; and skin reaction, which were to be a continuing cause of distress and a degree of debilitation which some patients found hard to bear.

Many patients commenced their radiation treatment with some degree of physical impediment, such as difficulty in swallowing, sore neck, chronic leukorrhea, bleeding per vagina and so on, and which were symptomatic of their cancer illness. These symptoms however, did not cause any pain or present any problem to the patients other than, as some complained "It was annoying to me." It was later, after commencing radiation treatment and having experienced fatigue and other debilitating side effects, that patients would begin to link these experiences directly to their treatment and which most had come to believe as being "harmful to our bodies." As well, the treatment symptoms were also identified with and in most cases, as causing the progression of cancer throughout their bodies. As patients were never forewarned that those same symptoms may also be a sign of progress in their treatment, they were presented with still more anxiety, which of course only elevated the patients suffering and which caused some patients to nearly give up and run away from the treatment.
CHAPTER 9

THE CANCER PATIENTS

Attitude Toward Cancer

Within Thai society, cancer is a taboo subject and one which is preferably left alone, with no one wanting to talk about it. It was found however, that in the Cancer Hostel community, things were quite different. Most patients were surprisingly aware of the extent of their own cancer illness, and were very open about it with the majority of them willing to discuss their feelings about cancer illness with me. At this juncture, it would be prudent of me to point out that in the case of every patient spoken to, whether in the form of an interview or during the course of daily chatter, I would ensure that on my part, the word cancer was not introduced into our conversations. Instead, I let the patients talk about their illness and their experiences as they were quite aware of their early symptoms. As it turned out, most of the patients themselves initiated conversations which would centre around the word cancer. Some patients however, preferred not to mention the word cancer directly, but rather, would make reference to their disease as "It", "That", or "My disease."

The Word Cancer

Mareng (Cancer) is perhaps one of the most frightening words in the Thai language and was, as Mrs. Von, one of cervical cancer patients, put it, "something that no one wants to hear." As well, it creates thoughts of human mortality, pain and suffering, hopelessness and rejection. It has been seen that many of those afflicted have expressed themselves in terms that show an almost overwhelming fear of the word cancer. As Mrs. Chuan, one of the patients with cancer of the cervix, stated:

Fear, I don't really know, It's just that when the word "cancer" is mentioned we experience a great fear. I've heard people say, that for the one who has cancer there is only the waiting for the day to die and that it can never be cured. That's a frightening thought.
Mrs. Nunn, another cervical cancer patient, gave her account:

I fear only that it's incurable. Before, I knew very little about cancer, only what I heard from the rumours, that no one survives this disease. Now, there is the fear of Aik [Mrs. Nunn meant AIDS, but pronounced it the way she had heard others do so when talking about it]. What is Aik?, we don't know about that yet.

Mrs. Utorn told of her fears that had troubled her from the early days of her stay at Cancer Hostel:

Cancer, is it really a curable disease? ... If someone gets cancer, will they ever be free of it? ... I am afraid that cancer really means death for me. ... I have a fear of it being incurable and that I must die.

Two weeks later, on the day that she completed her treatment, Mrs. Utorn again spoke of those fears, "I still fear the word cancer. I fear that for me it is incurable and that I must die."

Not all cancer patients became upset over the word cancer as became evident during a conversation at Cancer Hostel where one female patient, who was receiving treatment at one of the other treatment centres, would say:

I know very little idea about the word "cancer", but I do know that it has to have a bad meaning because I heard people in my village using the word whilst they were trading abuse with each other. During those shouting matches, they would call out, ei pak mareng [ei, in this context: abusive modifier adding strength to words meant as bad language. Thus, pak is mouth, mareng is cancer, hence: cancer mouth].

Because she lived in a very remote area which was isolated from the outside world and where no one in her village had or talked about cancer, this was the full extent of her knowledge on the disease. For her, cancer was no more than a disease which brought her from a far away village to the big city, on which she said, "If I hadn't contracted cancer, I would have no chance to see Bangkok. Sometimes I think it was good luck for me."
There were however, some patients, who although having knowledge of the disease, had no fear of cancer and displayed this attitude from the early days of their being in Cancer Hostel, retaining those ideals throughout the treatment phase and still gave no sign of changing their stance at time of discharge. As Mr. Prasert explained:

I have no feelings on the matter. It has no meaning for me. ... I believe it to be this way. Humans are born into a life and that life can just as easily be extinguished. It only matters as to which way that life is extinguished.

As well, Mr. Pratin in expressing his feelings during his first interview, mentioned, "When the doctor told me that I had cancer, things were no different for me. It is my disease, I could not run away from it." Ten days later, at a time when he was in agony with the pain from radiation therapy, he was again asked the same question on his feelings toward the word cancer, to which he replied, "I have no fear, why should I be afraid. What ever happens, happens."

Some patients, although having no initial feelings of fear, would later find that their perceptions of their disease had changed. As Mrs. Von outlined when asked about her feelings toward cancer.

I used to have no feeling about cancer. ... Four or five years ago, while I was in Raja Hospital [a public hospital located in the capital, Bangkok] for Thyroidectomy, I slept next to a patient who had cancer of the mouth. I didn't think anything about it because I saw her go on to be cured, she was in no pain and eating quite normally. Later, when I began to bleed a lot, the doctor told me that I had cancer and that I had to go to Siam Hospital for radiation treatment. At first, I didn't think anything of it. But now, I think this disease will cause my life to be shortened as well as being rejected by my friends and those in my social group.

She smiled, and tried to hide her feelings by allowing a little laugh to escape before continuing the conversation. It had become difficult for her to go on and she talked with tears in her eyes, "I don't think anyone can survive it."

As the comments of this patient show, the word cancer was not one that conveyed a sense of fear from the outset. But rather, as in the case of Mrs. Von, it was the patient's image of cancer that changed as a result of interaction with her family and friends within her community.
After communicating the diagnosis of her disease to her family and friends, Mrs. Von noticed that the attitude and reaction from those around her, had changed. She went on to say:

When I was sick with my Thyroid condition, there was no talk about it, but with cancer it's different, it seems that people talk about it too much and that makes me think that it must be worse. They didn't talk to me, they spoke to my husband and my daughter, but I knew that they were talking about cancer and how people with cancer must die. I knew that when I walked past them that they were looking at me. They looked at me like this. [Mrs. Von impersonated someone staring at something funny or strange].

Again, as the comments of these patients show, the feelings and psychological images aroused by the word cancer were individual. Their ideas changed from time to time and although their long held beliefs were conditioned by the impact of more current knowledge, they remained linked to form their present concepts of what cancer means. Those meanings however, were not always for the worse, especially for those patients who did not perceive of their illness as a major disruptive event, but rather, interpreted it as part of a normal existence.

Cancer and Other Illnesses

In trying to understand what the patients really thought about cancer and how they perceived its severity, patients were asked to to compare their illness with other previously experienced illnesses or with the everyday complaints that could be experienced by most people. The surprising results from these 'bench-mark' comparisons showed that many patients perceived cancer as being less severe than any of their previous illnesses, whilst other patients felt that cancer was no different than any other illness, as was the case for Mrs. Kesom, who was also a diabetic and who expressed these thoughts:

I think they are the same, I don't have any symptom that troubles me, either with my cancer or the diabetes that I also suffer from. Cancer or diabetes, there's no difference, I can eat if I want to eat, I can sleep, and I have not lost any weight.
There were some patients who felt that the symptoms associated with their cancer illness were less severe than those from any other illness that they had suffered. Mr. Adoul stated:

In my experiences with malaria, there's more suffering, and it's more painful and although I drank alcohol to ease the symptoms, it did not stop the pain and the shivering from being cold. But with cancer, I could stop the pain by drinking alcohol.

As well, Mrs. Sumarng had complained about her headaches and eye pain quite often during her treatment programme. Although she took the medicine as prescribed by the doctor, it didn't really help that much. During our conversations, in which I would attempt to engage her in talking about her cancer illness, she showed that she was more concerned about her eye illness than with her cancer. In one of our conversations she remarked:

I have no problem with my breast. It is the eye disease that upsets me. The doctor gave me some tablets for the pain, it worked for a little while, then the pain came back again. I don't know what to do. It's very annoying and I get bored with the situation as well.

In another conversation, Mr. Prasert would disclose, that for him, cancer illness was almost the same when comparing it with the other diseases that he had encountered, except that his present state of cancer of the tonsil, the cause of his inability to swallow any hard food, was making his life a little more difficult:

R: Is there a difference between cancer and another disease?
Prasert: It is difficult to say.
R: Tell me what you think.
Prasert: I think that cancer is the same as any other illness.
R: Can you explain in what way it is the same?
Prasert: It is the same in as far as it makes me sore and ache in various parts of my body. But this time, I'm doing it hard. For four months I have only been able to eat rice soup. It hurts me a lot when I try to eat boiled rice, whereas with other illnesses I could eat everything.
Mr. Pratin saw things differently when asked to compare his disease with one of the more common everyday illnesses that one is likely to catch. He related how:

It is different. I mean, if we catch a cold with high fever we feel the effects almost right away. But we know that we will soon begin to get well again. Well, Cancer, it goes on and on, there is no sudden heightening of its effects. But if we leave it to take its own course for too long, it will be difficult, very difficult to cure.

Cancer as a Suffering Illness

There were many ideas put forward by the patients when they thought and talked about cancer. The most common talking point was not the fear of death, but rather, the fear of the suffering associated with death. Mrs. Wanna, a cervical cancer patient, expressed herself in a way that was characteristic of how the patients related cancer, with death. She pointed out:

Certainly there is a fear of death. If cancer is a disease that spreads throughout the body, then I fear that everyone who has the disease must die from it. . . . I saw two cancer patients die from their disease. One had cancer of the abdomen. He had been to see the doctor and had undergone an operation. There was puss oozing from his wound all the time. He died in agony after ten days, crying all day and night throughout his ordeal. I don’t mind if I have to die, but I want to die quickly, without that kind of suffering.

Mrs. Boontoung’s thoughts on cancer and death were much the same. To her:

Cancer must be the worst disease that anyone could possibly have. . . . I’ve heard many people say that cancer is a disease where death comes slowly, where death is a gradual process. If I have to die, I hope for a sudden death. A slow death is suffering.

Mrs. Lumpoo put forward her perceptions on how she felt when faced with the thought of dying from her disease:

. . . itchy, tight, hot ulcer. It is more severe than TB. TB is also a disease where you die slowly. With cancer, it’s a rotten and foul smelling death. . . . I fear the progressive growth and that my body, as it is being eaten away
will cause rotten odours to be given off, I mean, the more that this cancer eats away, the more rotten the smell, then no one will want to come near me. My children will smell me and I will continue on in pain. I've told my children, that if I was suffering from a slow death and was in agony, not to be afraid of boaob [demerit], but to inject me with medicine to let me die in comfort. I have told them not be afraid to kill me. Then they won't have to agonize over their mother, and neither will I... I'm not afraid of dying, everyone must die. When it is time to die, even the King must die. Why should we have fear, when we are alive we should concentrate on living.

Mrs. Sumarn a sixty-nine year old lady with breast cancer, also related her feelings on cancer and the fear of a suffering death:

I have no fear of cancer. I only fear the suffering. It takes a long time to die. I knew one cancer patient who was in her old age. She didn't want any treatment because she thought she would die quickly. But, it took many years, the cancer eating away inside her body. It was rotten and smelt terrible. That really frightened me. ... I don't mind the dying, better than living with all the suffering really. I am not afraid if I have to die, even if it be from the radiation treatment.

Mrs. Samran, a cancer of the cervix patient (in the remission stage) gave this account:

It is fear. I have seen many cancer sufferers. I have a fear of death, the fear of my body rotting and smelling. I have heard many times, that most of those suffering from cancer, must die. Like phu yai [the headman of a village] from my village. He had cancer of the neck. At first, he was treated with yatom [home made herbal medicine, the same as yamor] and later, after coming here, he underwent radiation treatment and received about 30 doses. He then went to Rachaburi Provincial Hospital, but he was rejected, they didn't admit him. He knew he was going to die because his condition had worsened, his body was rotting and really smelt awful. He sensed that it was incurable, so he went back to our village and died at home, in agony.

It has been shown in the preceding accounts, that death was not the most feared event that was faced by those cancer patients, but rather, it was the fear of all the suffering which they associated with cancer illness and the social consequences stemming from their illness. To conclude the issue and support this finding, the account of Mr. Prasert is put forward as a typical patient response:
Afraid of death? No, I'm afraid of the agony though. . . . I'm not afraid of death. If I have to die, let me die. I only wish that I not die in agony. When I am in pain, I can't swallow my food and when I can't have my rice I get hungry. I want to swallow but my throat gets too sore. That's agony. As far as I have noticed and from the questions that I've asked, not many patients have the feeling of fear. They are more afraid of the agony.

Cancer as a Financial Disaster

With the one exception, patients of Cancer Hostel were decidedly poor who earned their living in a variety of labour intensive occupations where they would be paid for their labours on a daily basis and would rely on the money that they were able to earn to support their families. When they became concerned over their illness, they would try every conceivable means at their disposal in an effort at curing their illness. However, as they would find, for those suffering a cancer illness, there was no easy cure. Available sources for the treatment of cancer, especially the modern medical techniques of chemotherapy and radiation treatment, were only to be found in the major cities. In seeking this form of treatment, Cancer Hostel patients were left with no option, other than to be referred to those treatment centres in far off places. For them, the decision to follow the advice of a range of consultants and travel to Bangkok, would in one way or another, lead most into some form of financial difficulty.

As previously pointed out, most patients were poor and their income was solely dependent on their ability to provide their labour on the basis of 'one days work for one days pay'. For most patients, being forced to quit work regardless of the reason, was a most undesirable situation to be in, as most thought that they were sacrificing their support of the family in order to seek help and undergo treatment.

Although the costs involved in travelling and other associated expenses, even for the low income earner, were regarded as affordable, it was for many patients, enough to cause deep financial problems. Mrs. Nuchin was one of those affected:

When the doctor told me to come here for treatment, he told me that I didn't have to worry about the treatment fee, and that if I had no money I could ask for free treatment. At home, when I told my husband the news, he said that I had to come here to follow the doctor's suggestion, but how could I come here, we had no money.
Initially, it was difficult for me to understand how someone, even those from the poorest areas of Thailand, could be so affected by having to spend such a small amount of money. In a later conversation with Mrs. Nuchin, it would become quite clear as to how this additional expense could cause such a great upheaval in the financial affairs of those poor rural folk.

Mrs. Nuchin was from Si Sa Ket, which is one of the driest and poorest provinces in Northeastern Thailand. Most people in the more affluent areas, such as Bangkok, have a preconceived idea that all people from the dry northeast are poor. Whilst not always the case, it was certainly true for Mrs. Nuchin, who, to be able to make the trip to Bangkok, had borrowed five hundred baht, (A$ 25) from the headman from her village.

Normally, Mrs. Nuchin had no need to spend much money. Her husband had built their own house on a little piece of land, so they did not have to pay rent. This, for Mrs. Nuchin, "... was a long time ago when we were younger and we could work hard to get the money to buy the things we needed. Now, we have a family and things are little bit harder." Because of the very dry conditions in the northeastern areas, farmers found it increasingly difficult to grow enough rice, even for their own needs, as it was for Mrs. Nuchin, who would further relate, "We can't grow enough rice to last through the year and sometimes we have to sell some of our stock, or we go out to work as labourers in someone else's field to earn a little money to help." Her daughters and youngest son could help in the daily task of providing food and helped in the growing of vegetables and caring for the few chickens they kept. The two eldest sons were no help as they both lived in Bangkok and were unable to send any money to help in the situation where at home, "We just get by really, we manage."

The worry she felt for her children at home was a constant source of anxiety which was heightened one day when the phu yai (village headman) stopped by to visit. She would later tell me, "The other day when phu yai came here, he told me that my children did not have much to eat." Throughout all this, although showing signs of sadness and despair, Mrs. Nuchin did not ask for any special help.

For many patients, loss of regular income to feed the family also required a readjustment of family roles, where the spouse or siblings would be forced to take on extra work to make enough money, not only for their own survival but also to support the patients in their early attempts at seeking treatment. A classic example of this was seen in case of
Mrs. Meinten, who had been the main provider for her family of nine by growing vegetables for sale at the local market. Her husband was a part time musician who only found work during religious celebrations or when a fair or travelling show visited their village. Mrs. Meinten worked very hard for her family, the more vegetables she grew the more money she was able to make. However, as the price of vegetables had not been that good, she had no money left over that she could put away. The one good point was that she had no debt. After learning that she had cancer, her time in the vegetable garden became less as she had to visit the doctor fairly regularly. The vegetables were not as good as before and although her husband and eldest daughter worked hard, they were less experienced in the management of the garden and so things began to slip. During admission procedure, Mrs. Meinten was assessed as having the means to be able to pay for her treatment and as this was really not the case, she had to borrow money to pay the treatment fee. As a result of this debt, Mrs. Meinten was forced to take her youngest daughter away from school to find a job and help her to pay back the debt.

During the admission procedure, it was customary for doctors or the social worker to ask the patients if they had any money. It was just as customary for patients to answer in the affirmative, not so much as a matter of pride, but rather, for the fear of not receiving the best treatment if they answered "No" and conversely, by answering "Yes", they felt that they were assuring the better treatment. This 'Thai way' of denying the true situation would cause some degree of worry for those patients when facing the problem of where that money would come from. Therefore, at the very time when they had the chance to gain the benefit of hospital funded treatment, they would, for reasons shown above, deny their true monetary position and be assessed as having to pay. The initial assessment of having to pay was not truly binding on many of the patients, as it was seen that on completion of treatment, fees would be waived when patients could show that they really had no money. Others would not have to pay simply because at the end of their treatment, they were not asked, even though it had been noted on their files. As can be seen from these accounts, there is no system in place to correctly assess the patients true financial status or to ensure that all fees due, are in fact, collected.

Cancer and Relationships

Most patients had experienced the feeling of seeing their relationship with others change, once their cancer illness became known. Some of these experiences were happier than others and saw relationships become much closer. Some patients however, were distanced from others because of their illness. Patients who told that their relationship
had improved among relatives and friends, had noticed the change through the greater care
that their close kin provided for them, their relatives and friends came to visit more often,
and a more noticeable level of psychological and material support were offered to the
them. Mrs. Lumpoo, one patient who had noticed a change for the better, told how:

My daughter and my son in law told me that I didn’t have to go to work in the
rice fields any more, they would take care of them. . . . At first, I thought that
people would reject me as I had cancer, but when I went home after having my
operation [vulvectomy] there were many people who came to visit me. My
friends, my neighbours, my relatives, they all came to gave me support. They
came so often that my floor had no time to dry [a Thai metaphor referring to
the old custom of visitors washing their feet when visiting]. They did not all
come at the same time, they would alternate.

There were quite a number of patients who blamed cancer as being the cause of their
relationship problems. Some patients told that they were rejected by others, some were
rejected by relative, others by friends and acquaintances. As well, some patients simply
mentioned that were rejected by society in general. Others told how, that as a
consequence of their cancer and the resultant economic hardship, their relationships with
all those who had previously been part of their social network, had changed. An example
of this was seen in the case of Mrs. Nuchin, who believed that the reason for the
decreasing number of visits by her son, was because of his fear that she would ask him
for help with the treatment fee. A different set of circumstances existed for
Mrs. Tongpreow, who adopted an understanding view as to why her husband had
changed from being a good husband who was very active, attentive and had never been
abusive to her and the children, to one who slept most of the time and paid no attention to
the children and would at times, become withdrawn and display a rather sensitive mood.
This change was noticed on a weekend at home in an attempt to have a break away from
her radiation treatment course.

Mrs. Tongpreow told how she understood her husband’s change in behaviour and that:

It was because he was over-tired, and the effect of yamar [a stimulant]. He
works hard and when he becomes tired, he turns to using yamar to keep
himself awake and keep going at his job. His job entails very heavy work, the
truck would pick him up very early in the morning to go to the mountain
to cut bamboo. He said, that if he did not take that drug, he would not have the strength to work, and where else could he get the money to live on as well as for my treatment. I felt a bit noijai [hurt] when I heard him say that. I went back home to find a place to relax, for comfort, but it was not that way at all.

There were different degrees of rejection felt by the patients, from the already mentioned case of Mrs. Von, who had overheard the gossip in the local market of her village and where she had felt the isolation, to that of Mrs. Tongpreow where the degree of rejection was far greater and more than one would expect, in that, rejection not only effected herself but also her family. Mrs. Tongpreow recalled that time:

Before I got cancer, many people came to buy my food. It was really good, I sold out everyday. When people knew that I had cancer, no one came to buy my food. Later I had to close my shop. . . . It's not only other people who reject me, but my relatives also. My mother-in-law, my sister-in-law they all reject me and since I got cancer they have not yet come to visit me. . . . For me it does not matter, but I felt sorry for my daughter. She was also hurt by having a mother with cancer. She cried for me one day, she told me that she wanted to play with the children of my sister-in-law who lived not far away, but they did not want to play with her, she said they did not open the gate and let her in. They shouted at my daughter "your mother has cancer, your mother had cancer, your mother will have a short life." My daughter was really hurt.

Sexual relationships had also changed. Most patients, especially cervical cancer patients, told that they feared to have sex with their husband as they thought that it would interfere with the curing process or that it would cause other people to gossip about them. The fear of it being incurable and their concern of other people's feelings toward them, led most into refusing to have sex with their husband. Some patients told that they had not had sex at all since they became aware that they had cancer, others tried to avoid having sex, or as little as possible. However, patients felt that it was not fair for their husbands, and so, many of them allowed their husband to have sex with prostitutes or other women.

Mrs. Utorn explained:

I haven't slept [had sex] with my husband since I became aware that I had cancer. When I slept with him I suffered pain and there was bleeding. I fear that if I continued to sleep with my husband, my illness would get worse and would be the cause of it being incurable. I was also in pain. So I told my husband that I did not want to sleep with him. . . . Men like to have sex, so they aren't afraid. But women are afraid of the pain if they have sex. Why do you ask? [motioning toward the researcher] You don't have to worry. You
don't have the disease. . . . I told my husband to have sex with another woman, I know that it is very hard for a man to control his desire. I don't mind really, as long as I keep him away from me.

The Cause of Cancer

The questions "Why have I got cancer"? and "How did I get it"? were the most common questions asked by the Cancer Hostel patients. In trying to account for their malaise, the patients usually linked the time of the onset of their illness to the cause of their illness. As well, the meanings that they assigned to the cause, changed from time to time, depending on their perceptions and interpretations of the information that they received.

Another constant theme put forward by a number of the patients was the thought that perhaps their illness was due to a physical cause. In explaining the various links between a physical cause and their disease, patients would cover quite a number 'root cause scenarios' from which the physical causes of cancer could be placed into seven categories. Those being: (1) Kam (Karma); (2) Sexual relationships; (3) Physical change; (4) Chemical poisoning (pollutants); (5) Personal hygiene; (6) Phi (Spirits); and (7) Others.

A majority of the patients would claim that kam or baab (demerit) was a definite 'physical cause' of their illness. This belief is brought out in the following accounts: (It should be noted that in these accounts a number of words have a similar meaning. They are the words as used by the patients and no attempt has been made to standardize their use)

Mr. Pratin:

I think that things are like this, that we have to pay for our kam [demerit]. . . . I don't know the cause. . . . I do know one thing though, it is my time to be like this.

Mrs. Boontoung:

It is our baab [demerit]. If we had bun [merit] we wouldn't get it [cancer]. But, seeing that we have kam [demerit], we have it.

Mrs. Nuchin:
Cancer . . . , for me there is no pain, but there is a lot of bleeding when I work hard. . . . I always think that in a previous life, I made kam and I made baab, which is what I believe to be the cause of my disease.

Mrs. Tongpreow:

I believe in bun and kam. So, in this life I make sure that I don't do anything that would make baab. For example, if anyone asked me, to bash the fish head [to kill prior to cooking] I wouldn't do it, because I fear that my actions would go with me to my next life. I don't tell lies either, I fear . . . I fear everything since I became ill. . . . I've heard many people say, we suffer with a disease due to kam, because we have accumulated baab or kam made in a previous life.

Mrs. Chaun:

I cried, why me? Why not the others? Is it because I have baab, or kam? Other people comforted me by saying that it was normal for everyone to have baab and bun and so on. . . . What is the cause? We have bun and kam which come together, as do baab and bun [good comes with bad and bad with good]. It really does, we make baab in a previous life, then in this life we contract this disease.

Mr. Prasert:

I have read something about that and I have seen the advertisements which show that spirits and cigarettes can cause cancer. Why is it then, that non smokers and non drinkers get cancer? . . . You want to know how it works, don't you? I think it is because we are aware of changes occurring in the body. Concerning kam, there are certain actions which relate to illness, such as those bad actions accumulated in a previous life which at that time had not been paid for and which are carried over into this lifetime and must be repaid in order to free ourselves of that debt. . . . Yes, when we think like that, our heart has no suffering. To give an example. When we borrow money from someone and we have not yet paid it back we have that worry on our mind. If we pay off our debt, then our minds are bright and we are happy. But now, I'm still in debt. . . . You see, it is the same as in the previous life, where we committed those actions, and now in this life, we have cancer as a way to pay off our debt and become free from kam.

In referring to baab and kam most patients gave accounts of having to repay the debts accrued in a previous life and made only brief mention to repaying part of that debt in the same life. The following is an account where a patient makes direct reference to one
being able to repay debts of baab made in the present life, thus 'clearing the slate' within the present life. Mr. Sangiem put his views forward on why he had cancer at his neck (hypopharynx):

I think, that it was my making Baah. . . . Baab, this is how it is. When I was a young man, I drank spirits and once I ate a chicken which I had killed. I strangled the chicken till it died, then I boiled it. This baab is the cause of my disease and now I am repaying that debt with this disease.

As shown in these accounts, although all patients used kam as a way to account for their illness, it was individual in explanation and detail.

Having sexual relations was claimed by many patients as being the cause of their illness. Although it was not clear to them as to how this came about, they were quite certain that having sex was linked to their contracting cancer. Their accounts follow:

Mrs. Utorn:

In the past, I thought that leukorrhea was the cause of my disease. I didn't know the cause of leukorrhea, but now, I think that maybe cancer is the cause of leukorrhea. I still don't know where it comes from. Among the patients at Cancer Hostel, we talk about the cause of illness and yet we still don't know. Last night we talked about leukorrhea, many of the patients still don't know where it comes from. . . . It is partially true, I think, that my husband carried the disease and infected me and caused leukorrhea. . . . It has not only happened to me, it has happened to the others as well. But, I am not one hundred percent sure how the disease occurs.

Mrs. Meinten:

I don't think that man is the only cause of cancer. Since I've been here at Cancer Hostel, I have noticed that even younger and single women have cancer. But I don't know what the cause of my illness is.

Mrs. Chaun:

I think that having a husband is the cause of my disease. . . . Before, I had no symptoms. I was a widow for ten years, and when I remarried, this disease appears. That makes me think that it is because of having a husband. . . . I still think that way. . . . I asked the doctor, she didn't tell me anything.
Mrs. Von:

My husband would go to have sex with other women and was unclean. That means, that after he had been with another woman, I was left with leukorrhea.

Mrs. Mann:

After having an abortion, . . . I became pregnant again. . . . In the past, I earned my living by carrying rock for the road constructions where I received 10 to 20 baht a day. I used that money to look after my children. At that time, my husband drank a lot and went out with prostitutes. I had to work hard to get that money to look after the children. As I've said, I had an abortion and later, I had sex and became pregnant again while my uterus was still wet as the lochia hadn't dried out. This may have caused the disease. . . . At the hospital, I saw many patients with cancer.

There were some patients who blamed the contamination of their food by chemical preservatives as being associated with the cause of their illness. Some of their reasons for these thoughts were given as:

Mr. Adoul:

I think the cause is the poison from the environment, from eating raw food, it adds up to a large amount.

Mrs. Sumarng:

. . . in my parents time, no one had cancer. But now, after having been in Cancer Hostel, even a young student there has cancer. He had radiation treatment to his neck at Racha Hospital. I believe that the drugs that are injected into the food, such as vegetables, chickens and pigs, to keep it fresh, is the cause. People in the old times didn't do that. We eat that food and it all accumulates in our body. At present, we buy everything, like fish sauce. In the past we didn't have to buy it, we made it. Now, they put colour into everything to make it look good. It is all the colouring that is to blame.

Mrs. Mann:

I think like those who have said that we don't really know cancer. Some say it's a living thing, whilst others say it isn't a living thing. . . . It is my dirtiness. . . . I will explain to you openly, without shyness. After an abortion, I became pregnant again. In the past, I earned my living by carrying rock for the road constructions where I received 10 to 20 baht a day. I used that money to look after my children. At that time, my husband drank a lot and went out with prostitutes. I had to work hard to get that money to look after the children. I had an abortion and had sex and became pregnant again while my uterus was
still wet as the lochia hadn't dried out. This may have caused the disease. . . . At the hospital, I saw many patients with cancer. . . . Among us, many patients have recalled that when we were young and lived at home with our parents, we were never ill. But now, we have this disease. I mean, I believe that the vegetables we eat today without rinsing them are contaminated with chemical agents, but we can't see this with the naked eye. My brother once told me that he injects his goods to keep them fresh and to improve its presentation. . . ., try to look at it this way, even the people in the south, who are all rich, have this disease. What is the cause?, they eat good food, pork, chicken, but it's all injected with a medical substance. Country people are poor, we are too tired after working hard and prepare the vegetables to eat straight away, without rinsing them with water. That's how the disease happens. . . . I still think about the uncertainty of its cause. . . . Someone said it comes up by itself. In my heart I don't think that is how it happens. The more I think about it, the more I am sure that it depends on how people act, whether they make a lot of bun (Merit), or not much bun.

In some cases, the patients believed that the cause of cancer was linked to the observed physical change that was taking place in their body. These patients told how:

Mrs. Mai:

About two years ago I developed a lump here [under left armpit]. I had no feeling of pain. . . . After I gave birth, the maw bor rarn [a doctor practicing in ancient healing methods], was afraid that my milk would be obstructed and so she pummelled my breasts with hot compresses which contained medicinal herbs. She pummelled them so that the milk would run freely, you must ask the old people about this. . . . like young female breasts, they are hard and lumpy, aren't they. But, when you pummel them it makes them soft and the milk can then run better. . . . this side [right] is all soft, but this side [left], she couldn't soften it at all. The area near the left side is still hard. It's like a mass on another mass. That is the tumour, it grew from the unbroken, hard part of my breast.

Mrs. Samran:

I am getting better maw [patient refers to researcher as doctor, as rural people usually refer to all those connected with health care as maw]. I worry whether or not there will be a relapse. I went to consult maw Yarne [The cashier]. . . . I asked whether I would be rid of this disease. She said it depends on my tissue. How can it depend on my tissue maw? . . . I don't think that is correct, I don't think it depends on the tissue. It's like this, at first I already had the disease, then pass and blood. Cancer formed and built up a mass. On the way, as it travelled to the effected area, some broke off and lodged in other parts of my body [neck and armpit]. The radiation treatment only cures those areas at which it is directed and so, the disease will break out again in those areas which are not covered by that treatment.

Mrs. Von:
It may be that we didn't look after ourselves. ... I think of it in two ways. Firstly, My husband would go to have sex with other women and was unclean. That means, after he had been with another woman, I was left with leukorrhrea. As well, I was unclean, by that I mean that during my mensuration I used a piece of cloth from an old sarong to make a pad. Sometimes it was not dry after washing and I would use it wet. It was because of my dirtiness, but it was not really that dirty. I had no money, I wanted to save. ... I have thought this way since the doctor at Petchabun told me that I had cancer.

Mrs. Lumpoo:

... they [friends] said, "It's tumorous and will change to cancer. ... I don't know. It's itchy, tight and hot. It's ulcerated and has turned to chronic ulcer.

For one patient within the study group, cancer was inflicted by one of the many Phi (Spirits) that Thai people believed to be harmful to human beings.

Mrs. Geing:

The older people call it Phi Sabai. It isn't sore, it's painless. It lies dormant and if it goes untreated for a long period of time, it can cause death. There is a poison, we don't know what it is, but if we eat the wrong food the poison will dissolve in our body. The older people call it Phi Sabai, modern people call it nareng [cancer]. My grandfather and grandmother were often affected by it. Sometimes, Phi Sabai was in the form of a rash around the waist and at other times there was a blistering of the skin. The symptoms were not always the same, there were many kinds but it was all called Phi Sabai. One kind is where the ulcer is very large with an inverted centre and is green in colour. There was one sufferer in my village who did not seek treatment, just drank holy water when the ulcer ruptured. She reported to the hospital but was not accepted to be a patient, so she returned to our village and died at her home.

There were some patients who had no firmly held ideas about the cause of their illness but expressed their personal beliefs as shown in the following accounts:

Mrs. Kesorn:

It isn't an infectious disease, but if it is cancer of the mouth, it could be transmitted from eating food contaminated by that patient [cancer of the mouth patient].

Mrs. Wanna:
Why me? I do a lot of good things. . . . I don't believe that it is an infectious
disease. If it is, all the doctors and nurses would have contracted the disease.

Mrs. Nunn:

It's only the country people who have shown rejection when they heard that I
had cancer. I heard someone say "It's not transmitted". Is that true? Some
have rejected me though. But, maw [the lab technician] who took the blood
from us, he didn't show any sign of rejection toward us.

From the patients' point of view, it could be concluded that biological knowledge of their
illness did not play a major role in allowing the patients to make sense of the cause of
cancer. Rather, the patients used culturally inherited knowledge and a common sense,
albeit naive approach in their efforts to understand their illness.

Cancer and Treatment.

Another image of cancer held by the patients, was the noticeable variances in the
effectiveness of the treatment. As well, there were differences in the ways in which they
put their trust and belief into that treatment. Many of the patients believed that cancer was
an incurable disease, with others having thoughts of it being a disease that was difficult to
cure, whilst a minority of patients expressed their trust in the treatment and that it would
provide a cure.

When life, health and welfare were threatened by cancer illness, it was quite natural for
patients to consider every possible option and to feel that they were taking positive steps
towards 'improving the odds'. For patients, available cancer treatments would vary from
the herbal remedies to the sophistication of modern medical science. Knowledge of all
these treatments, presented patients with a confusing and often frightening choice, with
some treatments offering hope and were a genuine and positive support in their efforts at
coping with their illness, whilst others were reflections of their increased desperation in
selecting the right option.

Radiotherapy was the most feared form of treatment for the majority of patients during
my stay with them. This is partly due to the perceptions patients gained from the Thai
name for radiotherapy, chai sang, which is literally translated as meaning a generation of
energy (from a metal source) resulting in heat. For the patients, this translated as
something capable of burning or cooking their bodies. As well, the results of radiation
treatment, could cause an agonizing death and even interfere with the effects of other treatment such as when combined with the taking of herbal medicine.

The fear of radiation treatment among patients was rather high, especially in the early days of treatment with most believing that there would be pain and heat associated with that treatment. However, these fears were to decrease noticeably after it was realized that the actual treatment was a lot different than what they had initially perceived. Patients were helped to overcome by their being able to see other patients who were undergoing the same treatment and showing little sign of being burnt or cooked. Moreover, the noticeable improvement of their condition, such as reduced leukorrhea, no bleeding, smaller mass and so on, after only a few treatment sessions, helped patients build up their confidence in radiation treatment. However, after developing some symptoms from the side effects of their treatment and thinking that those symptoms were an indication of tumour progression, their confidence was again in question.

"The disease which is incurable" was how Mrs. Utorn expressed her feeling about her illness during the third week of her treatment. She continued, "This disease is difficult to cure, isn't it? Some say that it is cured after receiving radiotherapy, others say that it is not." Two weeks later, during her last day of treatment, she would remark, "I feel a lot better, but I still have a fear of it being incurable and that I must die."

Some patients, although receiving reassurances from others that their cancer would be cured, still held to their beliefs that this would not be the case and that they would succumb to their disease. As Mr. Adoul, who had undergone surgery during a previous treatment episode and had gone into remission, recalled "She [his wife] often said, that she was sure that I would be cured and be rid of this disease. But I thought, it can't be cured."

Mrs. Nunn, who was informed by her doctor that she had little chance of survival, put forward her ideas:

Cancer, my only fear was that it couldn't be cured. I had never seen any patients who had been cured. Even today, many patients who complete their treatment course, come back later because of intestinal obstructions as a result of the radiation treatment.

Later, during a group discussion, Mrs. Nunn asked her fellow patients, "Have you ever seen any cancer sufferers who have been cured?" On being assured by the other patients
that they had indeed seen survivors, Mrs. Nunn insisted, "There must have been very few."

As well, Mrs. Loaun, who at first thought that her cancer could not be cured, re-assessed her chances when she noticed an improvement in her symptoms. She related how:

The doctor told me not to run away whilst there was a chance to be cured. When I was here on my first visit, I didn't think that it could be cured. But now, I have no discharge, it has dried out and disappeared. It is dry now, nothing left.

There were some patients who thought that there was a chance that cancer could be cured. This chance however, was dependent on the type of treatment being administered and the stage that the cancer had reached. As well, it was the belief of many patients as well as their relatives, that surgery was one of the more effective forms of treatment that could help in the cure of cancer.

This belief was also shown in the case of Mrs. Von, a cervical cancer patient who had been referred to Siam Hospital by a provincial doctor for radiotherapy treatment. On arriving at Siam Hospital she was referred to another hospital because the radiotherapy equipment had broken down. In the following weeks, Mrs. Von was 'referred on' to a total of three other hospitals, each rejecting her admittance along with the accompanying reasons of, "It is already overcrowded here" or "We have no room" or "It's full here."

The time spent by Mrs. Von in trying to gain admittance to these hospitals and being rejected, was interspaced with times she spent at home after requests (which were really 'put offs') from those hospitals to "Come back in a weeks time." After having no luck in her endeavours, Mrs. Von was finally referred back to Siam Hospital where she again put her case to one of the doctors. She recalled how:

I had already been to three other hospitals but none of them had accepted me. I asked him what I could do and whether or not I could have surgery performed on my cancer as I had missed out on radiation treatment because of breakdown of the radiotherapy equipment. After he examined me, he told me that he could operate on me, but I would first have to have an injection through a vein in my groin area, after which he would be able to operate on me. When I heard him say that, I was very happy, because a rumour which had spread in our village and was widely believed by us, that cancer could be cured by surgery whereas to undergo radiotherapy was sure to shorten life.

Mr. Pratin, one of those who believed that there was a chance to be cured, although that chance be rather slim, explained:
From my experience, cancer is a disease that comes on slowly and gradually takes over and spreads throughout the body. I mean, it does not suddenly appear, it takes some time to develop. I know that if we ignore the early signs it would be difficult to cure.

Some patients believed that radiation treatment was an effective form of treatment, but was dependent on the stage of the illness and the part of the body affected. Mrs. Meinten, a cervical cancer stage 2B patient, related this belief to a past experience with her father’s illness. She told of the time when her father had gone to see the doctor, only to be told that the disease had gone too far and that nothing could be done for him. She believed that her illness was caught in the early stage and unlike her father, she hadn’t waited too long before going to see the doctor. As well, she also believed that "The cancer in a woman [uterus] can be cured easier when compared with the disease found in other parts of the body such as lung cancer."

Herbal medicine was another form of treatment that most patients believed could cure cancer. Although many patients had previously used one, or as in some cases, a number of the many varieties of herbal medicines available, they eventually found they did not work. However, most still held firm beliefs of the positive therapeutic effects to be gained from their use. In defence of those medicines and attempting to explain why they did not work for them, most patients would insist that it was their mistake in making the wrong choice from the many types and sources at hand and had taken the wrong one. There was also the belief that herbal medicine worked differently for different people and that if one particular medicine worked for one person, it did not mean that it would work for another.

Patients did not take herbal medicine whilst they were receiving radiation treatment, as most of them believed that these two treatments were incompatible and that their actions would work against each other. However, on completion of radiation treatment, many would say that they would continue to use herbal medicine, believing that it would eradicated cancer and prevent any relapse and were quite active in seeking out information on certain drugs from within their own ranks.
Mr. Pratin gave this account:

I will take yatom. I noticed that a couple of the women in my village who have had radiation treatment, take herbal medicine and if they do not take it, they would have to come back here for treatment again. . . . I've also asked some of patients here, to find out what sort of medicine they take. I also asked that patient, the one who had the very big arm [one female breast cancer had developed lymphedema on left arm], she said that she had undergone cancer treatment and that it was cured for three years, she did not know why it came back again. She said that she did not take herbal medicine.

There were a number of patients, who although professing their disbelief in herbal medicine, still showed their interest by listening to other patients talking about its effectiveness, as well as keeping some of the samples passed out by others, "just in case." An example of this was found during a visit to one of the patients rooms and where I had joined with some of the patients in sitting on the floor and listened to their rather animated conversations. Herbal medicine was again the centre of discussion with the 'for and against' arguments doing their normal rounds, when one of the patients produced a bag of herbal medicines and began to dish them out, with, "One for you . . . and this is for you . . . and this one would be better for you." Some accepted them more eagerly than others, whilst some, rather shyly, took them and along with expressions of reluctance, put them away in their bags. There were only very few patients who did not show an interest in herbal medicine and rejected all talk about it. Two of those patients, Mrs. Boontoung and Mrs. Mann had both used them for over a year and had later developed severe bleeding with almost fatal results. For them, herbal medicine was not the answer to their illness problems. This feeling was echoed by Mrs. Boontoung when asked about her feelings on herbal medicine:

I know that before I came down here I had already tried so many kinds, but none of them worked, it couldn't be cured. So what should I do next? Go back home and start taking it again, and waste my money and have to come back here again. I'd rather not to take it.
CHAPTER 10

COMING TO TERMS

Introduction

Patients had developed the feeling of being compelled to stay at the Cancer Hostel in order to receive or continue with the treatment that would cure their illness or to at least control their symptoms. These feelings of course, kept them institutionalized, having to adjust and come to terms with the existing situation rather than finding solace away from the treatment environment by escaping to the comfort of their own homes or those of friends or relatives. Therefore, in this chapter, the main focus will be on matters relating to the patients' adaptation to institutional environment pressures and all additional stresses and strains encountered during their stay at Cancer Hostel.

Patients as Institution Residents

Patients who were assigned to stay at Cancer Hostel, the temporary shelter providing accommodation and meals whilst receiving treatment from the Radiological Department of Siam Hospital, found that they came under the charge of two separate institutional bodies, with each taking active control over their daily lives whilst in those institutions. The situation faced by the patients, in which both institutions became involved in their everyday activities, was not much different to what Goffman (1961) called, the "total institution." That is, the institutions authorized total control over those assigned residents.

As mentioned in previous chapters, the process of inducting the newcomer into these institutions, whereby patients were briefed on what was expected of them in order to 'fit in', was an unconscious effort on the part of various staff members, to supplant a condition of total control over the patients from the very outset of their treatment days. Within this controlled environment, patients were limited in the ways of negotiation and would find it difficult to become an active part in the planning of treatment scheduling in their own cases. When treatment was prescribed, patients were given little chance to plan for other exigencies outside that of their treatment schedule. As well, patients found to their dismay, that the commencement date of treatment was set by the doctor, usually
during first contact and that they were not given any say in the matter. Although they would invariably try to put forward their case in order to make a smooth transition into the institutional environment, it was usually all to no avail. Mrs. Wanna told of her experiences in the early days of her treatment:

I had no time to prepare myself to stay at Cancer Hostel. On my first day here I went to see the doctor and after his examination he told me that I would be starting the treatment right away. When I told him about the difficulty I had in travelling, he arranged for me to stay at Cancer Hostel. But when I asked him if I could go back home and come back later for treatment, he said that I should worry about myself and concentrate on my treatment. Really, I wanted to go and get my personal belongings. I didn't think that I was going to begin treatment during my first visit, so I didn't bring my clothes with me. I had only one shirt to wear. I had to spend the money that my husband gave me to buy a cheap shirt and other necessities. Now, I don't have much money left. I'll have to wait for my husband when he comes down next time.

Patients also found that their freedom was limited once they began their treatment, with many patients, who were obliged to stay overnight in the hospital, complaining that being kept in the ward and not allowed to go out, even for a little walk, gave rise to a great deal of frustration. Mrs. Kesorn spoke of her concerns the day before she was admitted for her second intracavitary treatment:

I don't like to go to the sixth floor [Ward 6]. I don't like to feel trapped in a small area where there is no natural breeze. It's very stuffy in there. I asked one of the nurses if I could go for a walk downstairs and she told me that because of the hospital's rules, she could not allow me to do that and suggested that I go for a walk around my ward. How can I do that? There was nothing of interest in the ward to look at, there were only the sick patients and that made me feel unhappy. So, I decided that it would be best if I stayed in my bed area.

Cancer Hostel rules did not permit the patients to eat their meals or store food in their rooms, a point that was continually stressed by the house staff. The patients did not like this rule at all, and some were willing to chance the late evening snack from the food that they had bought from the local shops or that which they had kept from their evening meal. Others would not dare to break the rules even though they would quite often feel hungry and would go without until breakfast. With the evening meal being served at 4.30 pm, it was for some patients, far too early and followed too closely on their days treatment activities which had usually left them exhausted and unable to eat at that time.
However, for most of those patients, their appetites would return after having rested and freshened themselves up. This left them in the predicament of feeling hungry, but not allowed to eat to ease that hunger. As well, patients were quite often subjected to bouts of shouting from the cook whilst queuing for their meals, and were always wary of the 'explosive atmosphere' that existed in the dining hall on most days. This meant that conditions were not conducive to allow them to enjoy their meal and some would turn away from eating at that time and go back to their rooms.

Patients also found, that to follow the institutions rules was difficult and against their natural instincts of surviving the institutional experience through self-help or group collaboration, as well as making them dependent on people having little empathy toward those goals. For them, the rules of not having meals in their rooms or the storage of food in their bedside cupboard, for example, was an effort by the institution to inhibit their desire to help themselves and thus have total control over them under the guise of abiding by some unwarranted rule to keep the place clean.

There were other areas of daily institutional life, in which the patients felt that they were not in full control. Their lives seemed to be dominated on all sides by people who were out to make their own lot easier at the expense of the patient and his or her well-being.

When staying overnight in the hospital for treatment, patients were not permitted to wear their own night attire. For them, this was most unsatisfactory as the hospital-issue clothing which they were required to wear, was as Mrs. Utorn described, "not clean and was itchy when wearing it", or as Mrs Kesorn would complain:

It looked dirty from the old blood stains, I felt disgusted when I was wearing it, I don't know how many patients had already worn that clothing, I don't want to wear it. Besides, It was too small for me, the nurse couldn't find a bigger size, there seems to be only one size to fit all.

Whilst at Cancer Hostel, patients had to use their own personal items of clothing, but on venturing out from their rooms the patients were sometimes told to wear 'proper' clothing. On one such occasion, Mrs. Lumpoo, a woman in her late 70’s, was told by the staff not to wear her under shirt, an item of clothing which she usually wore at home, to dinner again. The reason given to her by the staff, was that "it looked untidy." She would later confide in me that, "At my place, everyone wears that kind of shirt, even to the market. No one there seems to think that it's untidy."
With only five to ten minutes of each day spent undergoing radiation treatment, the remaining hours of the long day would be spent either waiting for transportation to or from the treatment centre, or waiting to be called into the treatment room. The only break from this tedium being the treatment itself or a visit to the doctor for reasons either related on unrelated to their illness.

A situation had arisen therefore, where most of the patients time tended to be a non-productive and a non-stimulative bore. As well, it was felt by the patients, that their time was of little importance to those persons charged with the management of that time. This caused most of the patients some degree of anxiety and to think that their time was "seemingly worthless."

Long delays from the unexpected breakdown of the treating equipment would also present the patients with a time wasting, waiting experience. The hospital, normally without notice, would also reduce the treatment hours on the pretext of the treatment centre staff attending a ceremonial, or such like event in which they would be taking an active part. This would invariably lead to the postponement of treatment for some patients, and as the patients from Cancer Hostel were given low priority, they would normally be the ones to miss out, their treatment being re-scheduled to another day.

**Patients as Sufferers**

As illustrated in previous chapters, Cancer Hostel patients were confronted with significant issues surrounding cancer and it's treatment and which for most, would lead to further unexpected problems. The fear of suffering from cancer and its related treatment, combined with psychological, physical and socio-economic problems associated with their illness, led to heightened levels of patient stress. Mental anguish and anxiety associated with isolation, pain and suffering, along with their fear of death, as well as the economic threats of losing their means of income, repayment of loans to cover treatment costs, the loss of their house or land to service such loans, were just some of the additional problems encountered by patients. As well, the style of interaction between patients and staff, which derived from differences in social status based on power, knowledge and wealth, as well as the Thai social values influencing the beliefs and behaviour of patients and staff, tended to increase the distance between patients and staff and would further add to the stress already being endured by those sufferers.
However, regardless of what form the 'new environment' pressures took, the patients had to make some kind of adaptation to institutional life where their illness had removed them from their sphere of normal social activities and set them down in the institutional worlds of Cancer Hostel and Siam Hospital where they were subject to the the apparatus of medical science and supervision by an 'institutionalized' staff.

Coming to Terms

POSITIVE THOUGHT

One way by which patients came to terms with their stresses and problems, was by committing themselves to each other and to the hostel community in which they found themselves. Patients with similar health problems and similar social backgrounds, now shared their new found identity and their sense of belonging to the one Cancer Hostel community. With these positive thoughts, patients were able to channel their energies into the betterment of that community as well as generally feeling better about their own situation. For most patients, positive thought was an important factor in helping them overcome their problems and adding to their resolve, 'to keep on going.'

Many patients also mentioned that since their arrival at the hostel and in seeing so many other cancer sufferers who were in the same situation and knowing that they weren't alone in their illness, made them feel much happier. As Mrs. Wanna said:

I felt really hurt and upset when I knew that I had cancer, that's because I don't know anyone else who has cancer. I thought, why me, did I do something wrong? But now, I feel better, as you have seen here, there are many cancer patients who are receiving radiation treatment, I am not the only one.

For Mr. Pratin, seeing other patients undergoing radiation treatment led him to think positively about his treatment and was a step toward him believing that, maybe there was a cure:

I think, it can be cured by chai sang [radiation treatment]. If it can't be cured, then no one would come here for treatment. I have seen many patients receiving treatment so it must be doing something. I don't think about it being incurable. . . . It [cancer] cannot win out over sang [abbreviation of chai sang]. It must be cured.
Support from fellow patients who gave or referred positive information were the more frequent supportive ways by which patients gained benefit from fellow sufferers. Positive thought centred around their illness as being bad news and their ways of overcoming it, included, ignoring the bad news; not talking about it; making fun out of it; and talking about other things. Patient responses in turning away from the negative and concentrating on the positive included, "I don't think about it; We don't think about it, instead, we talk about funny things; Whatever happens, happens; I can't do anything about it; It's my karma; and I pray to Buddha everyday to help me be cured of cancer."

BUN KHUN

Patients were fully aware that they were in hospital as patients in order to undergo radiation treatment that would hopefully, bring about a cure of their illness or at least to alleviate their symptoms. They also realized, that they themselves had to take responsibility for their illness, just as they would for the debilitating side effects of their treatment and which were considered by them as being "our troubles alone." As well, patients saw the staff as receiving no real benefit from their task of providing the care and treatment in the fight against their illness, but rather, it seemed that they were always there, on the job and carrying out the unenviable chores that would directly benefit the patients themselves. Moreover, they felt an obligation that encompassed not only the staff, who "were very good and kind and took care of them when they were ill", but also, the institutional system that had accepted them into the treatment programme, given them a place to stay, provided them with food as well as providing the best treatment available.

The feelings of obligation that individuals felt toward the staff as well as the institutions stemmed from the notions held by the patients in relation to those things that had been done for them. To a Thai patient, the involvement of the staff in providing the treatment is bun khun which is understood as "any good thing, favour or help which is meritorious" (Podhisita, 1985, p. 39). Because bun khun assumes reciprocity (Phillips, 1970), it necessarily follows that when one does a favour for another, the other feels obliged to return the favour. As well, obligations felt toward acts of bun khun are highly valued and important within Thai culture. Therefore, at times during the course of their treatment, when patients felt obligated toward the staff, they would seek an opportunity to return the favour in order to express their gratitude. Though, under the circumstances existing at the time, there was little that a patient could do to show that gratitude and return the favour in kind. There were certain ways however, by which they could express their appreciation, one being for them to "be a good a patient, as good as possible."
My inquisitiveness over these sometimes complicated dealings, led me to questioning the patients about *bun khun*, as to what it meant and how it affected their relationship with staff. Later, when going over the transcripts of those interviews, it was found that my line of questioning used in gauging patients responses to their everyday encounters with those staff, fell into two categories, having either a negative connotation as in "What did you think when that was done 'to' you?" or the positive: "What did you think when that was done 'for' you"?

Patient responses to most of these questions contained words or phrases that highlights the sense of values that is associated with *bun khun*. To the questions posed in the negative vein, patients would invariably answer in the positive and use such words as "my duty"; "have trust"; "must obey"; "must not question"; and "accept that." These responses are a window to the inner calm of those who have overcome feelings of anger, frustration, or the negative attitudes felt towards various situations that have arisen, and by making allowances for the shortcomings of those who have infringed on their personal dignity, have shown or given kindness in return.

The responses of patients to acts of kindness were more easy to understand, as it was a common talking point among them of how they would repay the smallest act of kindness and ranged from simple pledges of being a good patient to returning with gifts to repay that kindness. In some cases the gift would be nothing more than raw pepper or bamboo shoots, harvested and prepared back in their own home environment expressly for the occasion when they would return to the treatment place and present those gifts as an act of repaying past kindness. As to what was regarded by the patients as kindness, would to others, be a task carried out in the line of normal daily work requirements. This was highlighted in the case of Mr. Adoul, who on seeing that the domestic staff had cleaned the toilet, made mention that, "No one has ever done anything like that for me before. It's very kind of them."

Once patients fell into the circle of a *bun khun* relationship, they were strongly tied by it. Quite often during my stay, patients showed no negative response to circumstances and situations that I would have no hesitation in calling "unbearable." For them, these tolerances were made easier through another Thai social value of, *ot thon*. 
The Thai quality of *ot thon* [to endure, show restraint] when faced with emotional and physical stress, played a most important role in countering those troublesome situations. For Thais, it is generally thought to be socially unacceptable to show any overt expression, especially within any personal or situational, face-to-face confrontation. With this ingrained value at the forefront of their unwritten code of behaviour, patients, on most occasions, would avoid expressing their feelings.

Because of these beliefs of restraint, tolerance and aversion to any overt display of feeling, most patients would not cry out when they were in severe pain, with the only outward sign of their discomfort being the clenching of fists, a facial grimace, a teary eye or to reach out and grasp the hand of the nurse. This became clear to me when observing patients during the insertion of the applicator prior to brachytherapy. As I would later find out during my more intimate talks with the female patients, this procedure was the most painful of all that they had ever had to endure.

An example of how strong the feeling of *ot thon* was and how it pervaded their every thought on how one must act, even during their most painful experiences, was shown to me when I remarked to Mr. Pratin, "I haven't heard you complain about any of the painful experiences that you have been through? Do you have any pain at all?" He replied:

Of course I have pain, especially when I swallow. But what is the point in complaining. We are human beings and one of the characteristics of being human is to have *ot thon*. There is nothing that a human cannot endure. To express your feelings, even though they are painful, does not help or make things better, they simply annoy other people.

Sometimes patients could not keep their feelings 'bottled up' and would relate their experiences of painful treatment encounters to their friends, only to be reminded of *ot thon* and the uselessness of complaining and what was expected as acceptable behaviour in these situations. Mrs. Tongpreow told of one such personal experience:

One night, I had not quite gone to sleep, I heard Mrs. Nunn and Mrs. Boontoug talking. Boontoug had tested to see if I was awake, she called "Tongpreow, Tongpreow, are you asleep?" Boontoug said, "She's asleep." Then, Boontoug spoke to Nunn and told her that I had complained to her about my pain. Boontoug then said that "everyone has pain." I know that I had complained to her, but this time the pain was not the same as it was
before. This time it was unbearable, it was so painful that I put my feet against the wall to brace myself against the pain. They did not have pain, that's for sure, if they did, they wouldn't be smiling after their treatment like they do. . . . I'm not a weak person. It was really painful. Normally I like to walk around, but this time I could hardly walk. . . . I couldn't walk.

The more acceptable means of facing this situation was for patients to contain all outward expressions of their feelings and show others that they have mastered the situation, or to turn away from and ignore the physical side of their painful experiences, or as seen with most patients, attempt to rid themselves of any pent-up emotion by redirecting their feelings into gossiping about other patients.

Ot thon was a means by which patients gained acceptance from all those involved in their social world. The rewards from this form of stoic behaviour were the simple compliments from fellow patients or the treating staff, of "Oh, you are a very good patient" or "You are very brave," or as on some occasions, a direct reference to their behaviour, such as "You are very good at ot thon." It was sometimes difficult for patients who were enduring great pain to exhibit this expected behaviour and in their more stressful moments, when they felt like they did not have the inner strength to show ot thon, would draw on other sources to help them win over their adversity. One means of achieving this was to gain strength by accepting the situation as kam, their fate.

KAM

One important means by which patients were able to overcome their suffering was to accept the outcome of their kam and so, let nature take its course.

In Buddhist doctrine, kam, the Thai derivation of sanskrit karma, is generally identified as merit or demerit. However, it is to be noted that in everyday Thai conversation, kam usually refers only to demerit. The law of kam, is that every action, be it good or bad, has its consequences. Action here means only intentional action and includes physical, verbal and mental action. Kam is a theory of cause and effect, of action and reaction. According to this theory, action produces its effect or result wherein a good action produces a good effect and a bad action a bad effect. Man's present existence is said to be conditioned by his action in the past. The Buddha says, as Nyanatiloka writes:
All beings are the owners of their deeds . . . , the heirs of their deeds: their deeds are the womb from which they sprang, with their deeds they are bound up, their deeds are their refuge. Whatever deeds they do-good or evil-of such they will be the heirs (Nyanatiloka, 1981, p 19).

The belief in the law of kam among Thai, in that the state of an individual's present existence is the consequence of his kam accumulated in previous lives, plays an important role in shaping beliefs and behaviour. This importance is reflected in the way that Thai cancer patients overcame their problems when faced with their life threatening illness. The way that they accepted the sufferings both from their illness and treatment was considered by them as their fate. However, most patients did not accept their kam in a passive way. Instead, they tried in their energetic determination to enlist the assistance of one or more of the numerous ways they thought would help them in coping with and defeating their illness. Of those many ways, merit making was one of the most popular.

The popular behaviour of merit making, as it appears throughout this study, is an attempt to eliminate their suffering through giving alms to Buddhist monks, or through the offerings of food, fruit, vegetables, flowers, candles, incense or money at the spirit house, in Cancer Hostel, and at the statue of the father of Thai medicine in the grounds of Siam Hospital. The patients motivations behind these actions were generally for the acquisition of merit so they may gain benefit in this life or be rewarded in a future existence. These offerings were normally accompanied by requests for help to alleviate their suffering, improve their condition or to enact a cure of their illness.
CHAPTER 11

LESSONS FROM THAI CANCER PATIENTS

Introduction

This study began with the broad question, "How do Thai cancer patients perceive their illness?" Very little was known about Thai patients own feelings on cancer and its treatment, as the practice of withholding the true diagnosis from the patients in Thai society, coupled with entrenched medical practices and beliefs and the failure to recognize the patient as having a legitimate point of view, have presented problems to all who have endeavoured to find the answers.

How to go about providing an answer on such an ethically sensitive subject would come after many months of reviewing the copious amounts of literature concerned with the study of people and the methodologies used in those wide ranging studies.

This study then, being concerned with understanding how people, in this case, Thai cancer patients, perceive their illness, lent itself to the selection of a form of anthropological field work grounded in the cultural concept. Therefore, in selecting an ethnographic research approach, whereby I placed myself alongside those to be studied and observed them whilst they were receiving treatment, would provide the answers to the research question.

In this chapter, conclusions are drawn and presented. As well, some of the general implications of the ethnographic study, that have been addressed in this thesis, were examined for their relevance to the ‘main current’ of cancer care. The results are discussed in terms of both empirical and theoretical contexts. In addition, the implications for cancer care, cancer nursing education and cancer nursing research, which is the basis of this study, are also briefly discussed.
Turning to Knowledge

This is a study of Thai cancer patients which focused on patients' conceptions of their illness and treatment and on their relationships with the professional medical system, their families, fellow patients, and acquaintances, during the course of their treatment. The following section is devoted to the conclusion which is drawn from this study.

This research shows that becoming a resident of the cancer shelter, was a trigger that helped cancer patients to overcome any initial reluctance, and to either commence or continue with radiotherapy treatment in order to complete the treatment course as prescribed by the referring hospital or health care centre. A look at the socially similar conditions which existed for patients revealed that they were, predominantly poor; from rural areas and with no shelter close to the treatment centre; or were having difficulty in coping with transportation for daily treatment, being either unable to afford the cost of travel or they were becoming travel-weary from commuting on a daily basis.

The theme coming from patients in their narrations concerning their health-seeking process as discussed in chapter five, provided the more significant information to understand patients' behaviour when suffering from cancer illness. It was clear that cancer awareness was the important influencing factor which prompted the patients to seek help from a modern medical system. The fear of cancer illness, especially the fear of an agonising death from cancer, necessarily forced the cancer sufferers into doing anything and everything possible to find a cure for their illness.

Most patients had elected to follow the doctors' recommendations of leaving their family and hometown in order to receive treatment at far off places. To do this, some would have to sell their property or borrow money, which they would use to provide for their stay at those centres. It was however, not until after the patients became aware that radiation therapy was the prescribed treatment, that many would turn to using herbal medicine as an alternative treatment.

Residents of the cancer shelter, including those who adhered to their doctor's recommendations from the outset, as well as those who had earlier resorted to herbal medicines, held negative attitudes toward radiation treatment. The prescribed radiation treatment was thought of as being too destructive and harmful, as well as bringing on an agonizing death.
Trust in the doctors' knowledge and their ability in curing cancer, was the reason that patients often gave for following the prescribed radiation treatment. Some patients mentioned that they did so out of respect for the wishes of a close friend. As well, a number of patients disclosed that they reluctantly agreed to continue with treatment after members of their family or friends had taken the first steps and forced them to initially undergo radiation treatment. On the other hand, family members, friends and acquaintances also took an important role in influencing patients' decision in rejecting radiation treatment. Poverty was a common reason given by patients as being an obstacle for them and which prevented any early attempt to seek help from any health resource. However, as was later observed, this was not an important influencing factor when patients were faced with the full realization of the severity and advancement of their cancer illness.

Another important finding from patients' stories of their health seeking process, was that doctors used different approaches in telling patients about their diagnosis. It seemed that either telling or not telling patients the true diagnosis was a strategy employed by them to ensure that patients adhered to their recommendations. That is, doctors at the provincial hospitals would usually inform the patients of the true diagnosis to highlight the necessity for quick action in seeking treatment, whereas treatment centre doctors, would hide the true diagnosis, not out of a moral sense of duty, but to prevent further stress being placed on the patient and to keep the patients at the treatment site.

Apart from patients' narratives, my participation in their everyday activities provided an understanding of cancer patients in a therapeutic environment. I have come to learn from the patients of Cancer Hostel, who underwent radiation treatment at Siam Hospital, that mareng (cancer) is one of the most frightening words in the Thai language, and is, as one patient expressed "a word that no one wants to hear." I encountered many other similar expressions during my stay, such as, "Fear, it's just that when cancer is mentioned we experience a great fear", and "For the one who has cancer, there is only the waiting for the day to die. It can never be cured."

Patients harboured many ideas and thoughts about cancer and they would often relate those beliefs in their everyday conversations. The most common talking point was not the fear of death, but rather, the fear of the suffering that is associated with death from cancer. On this, one woman divulged, "Cancer is a disease where death comes slowly, where death is a gradual process. If I have to die, I hope for a sudden death. A slow death is suffering." "Why have I got cancer?, and "How did I get it?" were the most
common questions asked by the cancer patients. As well, in trying to account for their malaise, the patients usually linked the time of the onset of their illness to the cause of their illness. It was also found, that the meanings that were assigned to the cause of their illness, changed from time to time depending on their perceptions and interpretations of information that they received.

The thought, that perhaps their illness was due to a physical cause was a constant theme put forward by a number of patients. In their attempt to understand cancer illness, patients had grasped at every explanation they had ever heard and considered it in relation to their own specific case. Most explanations were folk beliefs with some coming from lay persons and their own retrospective evaluation of their way of living by using culturally inherited knowledge and a common sense, albeit naive approach in their effort to make sense of their illness.

An overall review of patient responses as to the cause of their illness, showed that a wide range of beliefs existed amongst them. The reasons given included, *kam* or karma (in this sense, a result of negative actions in a previous existence); sexual relationships; physical change; chemical poisoning (pollutants); personal hygiene; and *phi* (spirits). It was also found that modern biological knowledge, which most of the health care providers used to interpret the patients' illness, was not recognized as a reasonable explanation by those patients.

During their stay at Cancer Hostel, patients would experience uncertainty as an everyday life event with which they would have to cope. Unfortunately, this uncertainty was due mainly to the mode of communication that existed between the doctors and the patients and was directly attributable to the firm belief held by the doctors, that a cancer diagnosis would unnecessarily upset patients and that the provision of too much information would tend to further confuse them. As well, it would strongly influence their decisions as to what information, if any, would be passed on to the patients. The inconsistencies in diagnostic information offered by doctors at both the provincial hospitals and the treatment centre, along with there being no confirmation of the diagnosis, put the patient into a more uncertain situation. The lack of any treatment information that would normally include such details as, type; course length; effects and side effects of treatment; as well as the failure to mention whether or not treatment fees would be charged, made the patients' everyday life all the more difficult.
It was not only uncertainty that cancer patients had to live with during their stay at the Cancer Hostel, as feelings of anxiety and fearfulness as well as the physical suffering from the side effects of their treatment, also had to be endured. For them, cancer illness was seen as life threatening and gave rise to bouts of uncertainty. As well, the terms "life threatening" and "feelings of uncertainty" were also to be found in their references to the radiotherapy treatment.

Patients, would frequently employ the strategies of positive thought, reciprocal acceptance (bun khun), stoic resistance (ot thon) and fatalistic acceptance (kam) to overcome their problems and were considered by some as being sources of psychological comfort. Most patients found, that apart from their own self-help, drawn mainly from the various strategies employed, their fellow patients were another source of help that assisted them in overcoming their problems during their stay in the Cancer Hostel. On the other hand, the staff of Siam Hospital and Cancer Hostel were not seen as viable social source of comfort and contact with them did little to diminish feelings of anxiety, fear and uncertainty.

One important observation made whilst I was with the patients, was that the social value of distancing only heightened the problems that beset them. This was seen where cancer patients, in any face-to-face contact with doctors or other staff members, seemed not to show any negative expressions. Patients tried so hard to foster a pleasant relationship with the doctors and assisting staff by neither complaining nor showing any outward sign of the anger, bitterness and frustration that they obviously harboured. To vent those feelings, patients found that the one thing they could do, was to gossip, in rather harsh terms, about those people. As well, patients would avoid having any non-care related association with them. It was not surprising therefore, that the doctors and staff found it hard to catch the real, unexpressed feelings of the patients.

Turning to the Methodological Issue

Of immense importance to me, was the fact that I was able to understand the real experiences of Thai cancer patients, experiences which they really did not want to share with any outsider. In getting to really understand these experiences, it was extremely important that I get as close as I could to becoming one of them. Therefore, by physically 'being with' those patients, establishing rapport, and gaining their trust, I was assured of my acceptance as an insider, and I was thus allowed to share in the experiences of their life encounters.
It was clear, that ethnographic study in the natural setting, as presented in chapter three, was the most appropriate approach in helping toward a better understanding of the problem at hand by searching for a meaning of cancer from the experiences of Thai patients. As well, being with the patients in the natural setting allowed me to converse with patients in a way that was not governed by a pre-planned methodological framework and permitted the pursuance of certain issues. This method was also most appropriate in helping me to decrease the social distance between myself and patients, which of course was important in allowing me to quickly become part of that natural setting.

When considering the process of psychological commitment that played such an important role in the lives of the residents of Cancer Hostel, I noticed that in situations where patients answered a direct form of questioning from myself as well as when interacting or communicating between themselves, doctors, nurses and other staff, many patients responded in terms of fulfilling Thai social form or the expectations of the immediate social environment in which they had become involved. With my early recognition that there could be an analytic problem associated with such an assumption and for the need to see beyond the immediate social situation, I am indeed, comforted in the knowledge that the reasonings behind my selection of an ethnographic methodology, were well founded and that the conclusions of my study support those original expectations. That is, to fully understand the experiences of cancer illness as encountered by Thai patients, can probably only be done by naturalistic observation and interpretation.

On the basis of my observational material, I fully anticipated, that worry, stemming from interpersonal relationships, would be the most frequent form of anxiety which would emerge from patients’ responses to interaction with other people. The amount of gossip which occurred within the Cancer Hostel community, their references used to slander, the touchiness that patients exhibited in their actual relationship with others, all point to this conclusion. However, interpersonal anxieties did not, as far as could be perceived through my daily encounters with them, interfere or effect the relationship between myself and patients.

Turning to Implications

On the basis of the findings of this study, some implications can be argued in terms of, the care of Thai cancer patients; the education of nurses; and further nursing research.
IMPLICATIONS FOR CANCER CARE

Being caught in the routines of both hostel and hospital, places in which they had no influence, patients became voiceless people and were assigned a passive role in a bureaucratic power structure. As well as being denied access to their normal means of expression, patients were subject to feelings of uncertainty, anxiety, frustration, fear, hurt and pain. The interpersonal relationships of patients and staff were very much like those to be found elsewhere in Thailand that derive from the differences in social status based on wealth, education, power, prestige, and resources (Golomb, 1985). This primarily vertical social status, tended to hinder, rather than encourage interaction between providers and patients. Most patients were distinctly aware of the class differences that existed between themselves and the providers and they were quick to point out examples of condescending behaviour on the part of modern medical personnel in general. Staff with lesser qualifications and standing within the institutional settings were notorious for using their bureaucratic position to demand respect and compliance from powerless patients, more so those who were perceived as being from rural areas or poor backgrounds. Patients also felt that these members would use every endeavour in distancing themselves from the stigma of cancer and its associated treatment procedures. As well, many staff agencies were regarded as exploitative rather than charitable by patients of the Cancer Hostel. These feelings of rejection, distancing and isolation made the patients' position almost untenable in the sense that if the patients had not shown such a strong will to survive and overcome, they would surely not be blamed for wanting to opt out of such an oppressive environment.

The mainstream providers' idea of patient management was very much based on the provider remaining detached, with most providers remaining strictly objective in their views aimed at delivering a complete treatment regimen rather than attempting to understand the meaning of illness for the patients or to place it in the context of the patients' culture. Patients' subjective matters such as feelings and relationship, were excluded from consideration. Providers concentrated on the technical aspects of care which diverted them from the patients' inner world, an aspect of illness that was not routinely forced on their attention. Patients' concerns and criticisms over the providers' neglect of their experiences of the complexities and discomforts of cancer treatments (including radiotherapy and chemotherapy) and which were used as examples of case material for this study, have already been illustrated.
Patients were continually making sense of their cancer illness and treatment in complex ways. Patients’ beliefs and ideals about their cancer illness derived from their own stock of knowledge and beliefs which were closely linked with folk beliefs, culturally inherited knowledge and a common sense, albeit naive approach in their effort to make sense of their illness. These beliefs and ideas were not static and changed over time, and it was therefore, not surprising that the same patients talk about their cancer illness and treatments in different ways at different times. As for all who experience and reflect upon illness, it would appear that the underlying meaning of many patients' accounts about illness and treatment were quite different than those of the providers.

Most illness symptoms and effects of treatments were often not attended to or clarified by the doctors. Therefore, the patients had latitude to invent cause and develop misconceptions, or to confirm a large number of potentially competing assumptions about their treatment effects. To analyze the meaning of sensations, patients turned to their social support system for affirmation of their beliefs. It appeared that patients did not seek information from their doctors to understand their symptoms and effect of treatments, but rather, sought resources that would support their personal explanation for those situations.

The early cementing of harmonious social relationships meant that most patients sought information from within their social group and attributed fellow patients with having helped to reduce the uncertainty surrounding their illness by defining the situation, offering clarity, or giving relevant suggestions for action. Patients preferred to share their ideas and opinions with fellow patients and constructed their meaning through social comparisons in which one compared symptoms to those of others and formed meaning based on self enhancing knowledge or interpersonally supported views of mastery and control over the threatening symptoms. Guidance from providers was mostly oriented toward treatment outcome and objective clinical evidence, and did not help in the interpretation of meaning by the patients.

The implications drawn from these findings concerning cancer care suggests, that if one goal of cancer care is to provide holistic care to cancer patients, a conceptual approach to practice is necessary to take the cultural issue into account. These findings support the position that most of the problems that arise in the area of cancer care in Thailand, came mostly from the providers inability to reach an understanding of the meaning of illness for patients, nor were they equipped to deal with the problems experienced by patients.
Where patients have reported for treatment far too late into the course of their illness or have turned to alternative treatments, or discontinued their therapeutic regimens, they were subjected to blame for misunderstanding or having incomplete knowledge about their condition. However, it would be unfair if blame was rested solely at the feet of the patients, as providers, in failing to understand the patients in a socio-cultural context and for not attempting to communicate with them in order to win their co-operation, must equally share or at least accept part of the blame.

In the treating institution at the centre of this study, there is an obvious a need for the promotion of a health care provider-patient partnership, one of negotiation and mutual agreement in the development of a plan of care (Given and Given, 1984) and where satisfaction with health care provider, communication and the continuity of care, will enhance any effort to promote on-going cancer therapy in that therapeutic partnership.

Ignoring patients perceptions of cancer illness by trying to bring illness into the providers' own world and to interpret the illness in terms of a pathological frame of reference, is often seen as unsatisfactory by patients. Providers must become good listeners, as it is through attentive listening and picking up the cues, which invites and encourages an openness by the patients and is the process by which providers are able to understand the patients expectations, fears and feelings. This must be the aim of Thai health care providers in their dealings with Thai cancer patients who are at this time, rarely encouraged to express their more explicit feelings.

By improving communications in this way, the provider can enter the patients' world and to see cancer illness through the patients' eyes which leads to improved patient-provider interactions and results in a better understanding of cancer illness and treatments.

Also, by listening to the patients, nurses can get to understand the patients' perspectives on cancer and treatment. Once nurses come to understand the patients, strategies to develop nursing intervention such as appropriate teaching programmes can be implemented, which will ultimately lead to better patient care. As a mediator, nurses can facilitate in patients' receipt of informative support from the doctors by helping in the preparation of appropriate questions concerning their illness. Finally, nurses can also act as a liaison in doctor-patient communication network by helping patients to understand more about their illness and treatment through interpretation of actual or implied meanings.
IMPLICATIONS FOR NURSING EDUCATION

The findings in this study reflect that providers, including nurses, were ill prepared to enter provider-patient relationships and to understand the patients who were from a cultural and social background different than their own. These existing differences between patients and providers were seen in terms of social status, power, and resources. Nurse educators who are involved in the preparation of nursing programmes, especially for cancer nursing care, need to be aware of the cultural differences that exists between patients and nurses and need to design curricula which build on the knowledge of the human phenomena of culture. It is certain that efforts have been made to incorporate cultural content into curricula of professional nursing programmes within Thailand. However, it is felt that this content has been insufficient and of a generalized nature, as well as being rather difficult to adapt into practice.

IMPLICATIONS FOR FURTHER NURSING RESEARCH

It is clear that nursing research should be focused on significant clinical problems which are grounded in patient experience and that studies should be designed toward building a body of knowledge (Moody, 1990b). This study had the job of doing just that. In the field of cancer nursing, especially in Thailand, there is very little knowledge that addresses how patients perceive and respond to phenomena on cancer illness. The knowledge emerging from this study will be the first step into providing an insight into cultural responses to cancer of the Thai patient. However, there is a need for much more knowledge which will require extensive research and which must be undertaken in order to begin to build a body of knowledge that is seen to be sufficient in this area. This is fundamentally so in the cause for a more enlightened approach to cancer nursing care in Thailand, as it is through organised research studies which continually probe the varying ways individuals view the world, that culturally specific care can be designed and implemented.

Although conducting studies in the natural setting is challenging, it also allows the researcher an open approach to the problem being investigated and rather than being held back or dictated to by a specific experimental hypothesis that involves the use of tested instruments or statistical formulas, the researcher follows emerging ideas throughout the progress of the study and is free to develop and analyze a conceptual framework to answer the research question. This method therefore, is invaluable for the nurse-researcher who seeks to understand and explain what takes place in the realm of patient care from a position that reflects the real situation.
Final Conclusion

Cancer is a complex disease which cannot be understood by using only scientific knowledge. Understanding its complexities must extend into the socio-cultural sphere where the disease holds a unique and different meaning for every culture, as well as for every individual within the culture group, and which includes the difference between nurse and patient. However, in our understanding of the complexities of cancer and how it permeates into the very fabric of our social structure and relies increasingly on modern medical science to provide a 'technological fix', it is probably wise, to once in a while, sit back and reflect, as did (Meares, 1977, p.2):

Cancer.
Most die.
Some live.
Why do some live?
Medical science of course.
Perhaps.
But not the whole story.
APPENDIX

CHARACTERISTIC OF CASE STUDIES

The characteristics of the twenty-one case studies are as follows:

Table 1: SEX, DIAGNOSIS and AGE

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<th>60-69</th>
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<td>-</td>
<td>-</td>
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<td>Ca Base of Tongue</td>
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<tr>
<td>Ca Tonsil</td>
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<td>Ca Esophagus</td>
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<tr>
<td>Ca Hypopharynx</td>
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<tr>
<td>Ca Tongue</td>
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Key: Ca = Cancer
     Cx = Cervix
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<th>Table 2: MARITAL STATUS, EDUCATION and OCCUPATION</th>
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<td>None</td>
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