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COMPLIANCE
FROM THE PERSPECTIVE
OF TUBERCULOSIS PATIENTS

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ABSTRACT

Using a phenomenological approach, a study was undertaken designed to extend understanding of patient compliance by interpreting subjective experiences of people following treatment for tuberculosis in their own homes.

The progress of patients from the beginning of the illness until treatment is completed was conceptualised by using a patient career model, covering four main stages: onset of illness, period of hospitalisation, ambulatory care, and cure. The study focused on the ambulatory stage, during which the patient manages the regimen at home. Compliance with the regimen is critical if the end-point, cure, is to be achieved.

In-depth, unstructured interviews were recorded in their own homes from twenty-two patients resident in one metropolitan area. Men and women of varying age, ethnic origin, and socio-economic status were included. Supplementary data were obtained from family members, health care practitioners, and records. A modified form of comparative analysis yielded a rich pattern of themes in four main areas of concern. These were compliance with medication regimens in contrast to compliance with lifestyle recommendations; compliance in home environments and the role of family members; patient education and preparation for compliance; and the subjective experience of being ill with tuberculosis.

Although overall rates of compliance with medication regimens were found to be high, findings of the study highlighted the difficulties in measuring a multidimensional phenomenon as it appears from the outside without also interpreting the inner perspective.

Taking the patients' perspective on compliance, findings of this study suggest that present practices to encourage compliance underestimate the ability and motivation of patients to be actively

involved in promoting their own recovery, and that of other family members to assist them,

Patients recognised the period of hospitalisation as a time when they learned to manage their own medication regimens. However, they perceived themselves as being inadequately prepared for the contingency decision-making which was often required after discharge. Patients' explanations suggested further that opportunities for patient education in self-care were underutilised by health care practitioners.

Patients also perceived a failure by practitioners to recognise and deal with their subjective experiences of having what they saw as a serious and stigmatising illness. Patients were left with unresolved anxieties and uncertainties which, though not directly interfering with compliance or recovery, are not conducive to developing self-care capacities within holistic health care.

In conclusion, the simple patient career model is elaborated to take account of contextual influences and patient perceptions. The importance of the hospitalisation period for preparing ambulatory patients to continue the course of treatment highlights the need for health care practices to better facilitate the transition of the person from one stage to the next. Specific recommendations for practice and for further research are included when the implications of the study are summarised.

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GLOSSARY OF TERMS

PATIENT	Persons who have entered the health care system, and consulted practitioners within that system.
AMBULATORY PATIENT	The term is used in the study to refer to patients who have been discharged from hospital, but are continuing with the treatment plan on an ambulatory basis.
PRACTITIONER	Persons qualified and authorised to provide health care services to patients. Unless otherwise specified, the term refers to medical and nursing personnel, as they are involved in the prescribing of regimens and recommendations, in preparing patients to follow regimens, and in follow-up supervision of patients. When it is necessary to specify the kind of practitioner to whom reference is made, appropriate terms are used.
REGIMEN	The treatment plan, that includes prescribed medication, and other recommended therapy and practices, are included in this term. "Medication regimen" refers to prescribed medication only.
HEALTH CARE PLAN	The term refers to a broader range of recommendations than those prescribed for recovery from disease or disorder. Included here are lifestyle issues and practices that contribute to the maintenance of health and wellness.
PARTICIPANT	The twenty-two tuberculosis patients who agreed to participate in this study.
RESEARCHER	The nurse-researcher who conducted the study.
A NOTE ON PERSONAL PRONOUNS	In the report of this study, when the gender of the referent is known, the appropriate personal pronoun is used (e.g. him, hers). Otherwise, the masculine gender is used consistently to refer to persons in general, both male and female. The decision to use this more traditional convention was made in the interests of readability. The author is sympathetic to efforts to eliminate sexist bias in language, and therefore hopes that the choice exercised in the writing of this thesis is accepted in the spirit in which it is intended.

CHAPTER 1

INTRODUCTION

AIM OF THE STUDY

The aim of this study was to contribute to the understanding of the nature of patient compliance in the context of tuberculosis treatment. The perceptions and subjective experiences of patients were investigated as a means of interpreting their compliance with prescribed medication regimens and other health recommendations.

BACKGROUND TO THE STUDY

Need for Research into Compliance:

Patient compliance with medication regimens and other recommendations has been a prominent issue in both health and social sciences over recent years. This interest can be traced to a number of influences which are outlined below.

There is a growing trend toward general hospitals being used predominantly for the treatment of acute episodes of illness. At the same time research has increased the range of drugs available, which, provided they are taken over protracted periods of time, cure or effectively control certain diseases. Together, these two developments have resulted in increasing numbers of people being given responsibility for continuing their own treatment at home (Marston, 1970). At the same time, there is general agreement in the recent literature that rates of compliance are disturbingly low (Becker, 1979; Marston, 1970).

Failure to comply is not only wasteful of health resources, but also it has potentially serious consequences for the individual patient for whom the disease process is not arrested, and for the population which is not being adequately protected from a communicable disease (Becker, 1979).

The experience of the past two decades has demonstrated that unreliable compliance with therapeutic regimens is a worldwide problem that has adversely affected programmes to control such communicable diseases affecting man as malaria, leprosy and tuberculosis (Sbabaro, 1980).

The issue of compliance is further complicated by the increasing emphasis that is being placed on relationships between lifestyle and health. Compliance has now come to mean more than following a prescribed medication regimen. There is concern also with prescriptive and proscriptive recommendations aimed at modifying the person's activities in the direction of more healthful behaviour. In this broader context, the complexities of compliance behaviour have become even more evident (Haynes, 1979). It follows that health care research needs to be concerned not only with finding new ways to prevent, diagnose, and treat illness, but also with questions of how people can be assisted to comply with medication regimens and other recommendations.

Current State of Knowledge about Compliance:

Within the past decade several extensive reviews of the literature on compliance have become available, including an exhaustive evaluation of all hitherto published research on compliance (Sackett and Haynes, 1976). After critically reviewing 185 original studies, it was concluded that there was no single or simple explanation for the wide variation of rates and suggested determinants of compliance reported (Haynes, 1976). Cohen (1979) posits that the limitations in being able to generalise across studies, associated with the paucity of consistent patterns emerging in findings, is not attributable to methodological weakness. It is suggested, however, that most compliance studies have been conducted in the context of clinics, whereas behaviour takes place in the domestic context. In fact, only one community-based study was found in the review.

The premise that compliance as a phenomenon is comprehensible only in terms of contextual relationships

indicates that a study of the behaviour in the setting in which it occurs is appropriate. It has further been suggested that because the present understanding of compliance is very unclear, it would be more fruitful to investigate several factors simultaneously (Marston, 1970). For these reasons, a phenomenological approach was employed in the study. This was appropriate for use in the domestic setting and allowed interrelationships between a number of factors to be investigated in context.

Compliance in Relation to Tuberculosis Management:

Tuberculosis (abbreviated to Tb) continues to be a public health problem, even though the availability of preventive measures and effective therapeutic measures, along with an overall improvement of the standard of living, have resulted in a decline in the number of new cases being reported in developed countries (Essex-Carter, 1979). Compliance failure, resulting in inadequate treatment, has been identified as the most serious obstacle to tuberculosis control in developed countries (Addington, 1979b).

Personal Concern about Compliance:

The researcher's interest in patient compliance was aroused while working in a health services programme in a developing country. The concerns of the programme were the control of leprosy over an extensive region, and the development of an integrated Tb control and community health project in a limited area. It became evident over time that the major factor accounting for failure to achieve control of communicable disease through what appears to be soundly planned and implemented programmes was the high rate of patient drop-out from treatment. The orientation of the present study toward explicating the patients' perceptions of the situation also stems from this field experience in a practice setting.

The researcher was personally involved also in a mother and child health programme, with an emphasis on nutrition and child-care education, and again, the main reason for limited

effectiveness was poor compliance with recommendations. This occurred even when the resources for carrying out recommended changes were available to clients, and further, that these changes were not inappropriate within the cultural frame of reference of the families concerned. Thus patient compliance emerged as a significant factor in determining the effectiveness of health services, but one for which the complexities, although appreciated, were little understood, especially from the patient's perspective.

COMPLIANCE AS A VALID CONCERN FOR NURSING

Haynes (1979) has pointed out that two groups of health professionals who have taken a lead in investigating and intervening in compliance problems are nurses and pharmacists. In her seminal review of compliance literature Marston (1970) indicated the potential in the nurse-patient relationship for enhancing compliance. In a more recent discussion of nursing and compliance (Hogue, 1979), it was recommended that strategies concerned with compliance need to be developed from the patients' perspective and within the framework of holistic patient care. This is consistent with much of the philosophy currently guiding nursing practice, but there remains a need for more knowledge generated by research conducted within the same framework.

The focus of clinical nursing enquiry is not disease or disability, but the person, and his behaviour in situations of health as well as those of illness (Schlotfeldt, 1971). As stated previously, behaviours related to health and illness, including compliance with practitioners' recommendations, are complex phenomena. Therefore, understanding is most likely to come from investigations conducted under conditions which allow this complexity to be expressed, namely the contexts in which the behaviour usually occurs. Quint (1967) and others (e.g. Rubin and Erickson, 1978) suggest that field research is a particularly valuable approach for interpreting human behaviour in natural contexts.

An understanding of patient compliance is desirable not for its own sake only, but also to provide guidance for nursing practice.

Benoliel (1977) emphasises the importance of such knowledge being empirically derived. The inconsistent and even contradictory findings of compliance studies suggest that a fresh perspective on the phenomenon is required. Stern (1980) advocates the use of an interpretive research approach in order to increase the probability of gaining the desired change of viewpoint. In contrast to the static conditions of the hypothetico-deductive mode, here the researcher looks at on-going processes and interactions in the natural setting. She goes on to say that the likelihood of distinguishing facts from assumptions is thereby increased, and the fresh insights into a familiar setting that are gained are likely to be useful in guiding practice.

The great advantage of an interpretive research approach is that it requires the researcher to attend to the patients' explanations and interpretations of the experience, including their perceptions of the total situations (Anderson, 1981). An appreciation of the meaning which compliance has for patients can provide that fresh perspective advocated above, so making comprehensible to practitioners what previously has been unclear, and even baffling. The provision of more appropriate care would thereby be facilitated.

From a nursing standpoint the purpose of the study was to interpret compliance from the patients' point of view, so as to advance knowledge about how patients and their households cope with regimens and recommended lifestyle changes. Recommendations for nursing practice, when made from such a knowledge base, would be both appropriate to meeting patients' needs as they occur in the social setting, and consistent within a framework of holistic care.

SCOPE OF THE STUDY

In summary, a field research approach was employed by which in-depth qualitative data was obtained by interview from 22 patients currently taking treatment for Tb on an ambulatory basis. The sample was representative of adult Tb patients. In addition, supplementary and corroborative data were obtained from other members of patients' families, and from practitioners.

The development of person-centred approaches to assist patients to adhere to health recommendations requires that the meaning and experiences of compliance from the patients' perspectives be understood. The focus on compliance in relation to Tb treatment was seen as appropriate for reasons that the therapeutic regimen is prolonged, the treatment plan includes a range of recommendations, and compliance is obligatory in order to achieve control of the disease.

In approaching the study of compliance phenomenologically, in-depth data were generated from which differential meanings ascribed by patients to a variety of recommendations could be uncovered. Data obtained in the social context allowed naturally occurring interactions and relationships to be identified, in particular the implications which the diagnosis and treatment have for other members of the household.

It was assumed at the outset of the study that patients receive assistance with obligatory compliance over a protracted course of treatment. The chosen design ensured that within the study it was possible to explore not only the experiences of patients in complying with treatment in the domestic context, but also their perceptions of the way practitioners prepared and assisted them in complying with treatment.

Another important advantage of investigating compliance in-depth and in context is that it allowed the meaning of compliance to be interpreted in relation to the meaning of being ill with Tb. As a consequence, the significance of compliance with medication regimens and co-operation with other recommendations, in relation to other health and life issues, could be interpreted from the patient's perspective.

STRUCTURE OF THE REPORT

The report is presented in two parts. In the first part, the introduction provides the background to the study. Chapter two draws a profile of tuberculosis including a discussion of clinical

manifestation of the disease and treatment regimens. The "patient career" provides a conceptual framework for discussing treatment, and reference is made to the psychosocial implications of the disease for the patient. Chapter three contains a review of relevant literature on patient compliance. Particular emphasis is given to material from nursing literature. The design and methodological approach used for the study are presented in the last chapter of this section.

The findings of the research are presented in the second part of the report. Throughout the four chapters in which findings are reported, evidence for conclusions and discussion of findings are presented together. In the first of these chapters, compliance is interpreted as a response of patients to prescribed regimens and proscriptive recommendations. Then, in the following chapter, patients' experiences of compliance in the domestic environment, and in the context of their families, are reported. Patient compliance is here seen not as passive adherence to prescriptions, but as a process by which patients make decisions and develop strategies for themselves to ensure medication is taken.

Discharge of the patient from hospital marks a change in status from being an inpatient, when social responsibilities are suspended, to that of ambulatory patient, with a resumption of normal social responsibilities as well as the responsibility for continuing treatment. In Chapter seven the preparation and assistance patients receive to enable compliance after discharge is discussed in relation to the concept of status passage. Patients' perspective on the importance of compliance with therapeutic regimens in relation to the illness experience and health concerns is interpreted in Chapter eight.

In the final chapter, patient compliance in the domestic environment is conceptualised as an aspect of self-care, supplemented by cover-care provided by persons close to the patient. The patient is prepared for compliance during the hospitalisation phase of the patient career. By conceptualising compliance in this way, strategies to improve compliance need to be orientated toward enhancing, and not undermining, self-care and cover-care behaviours. Recommendations which the findings give rise to are made in relation both to guiding nursing practice and for further research.

CHAPTER 2

PROFILE OF TUBERCULOSIS: DISEASE AND MANAGEMENT

Tuberculosis remains a public health problem even though a range of effective therapeutic regimens are now available, and means of protecting the healthy population from infection are carried out. However, the application of these measures has brought about changes in the incidence and management of Tb, and these will be discussed below. Following the account of treatment, reference is made to psychosocial implications of having tuberculosis, which persist in spite of improvements in treatment and prognosis. Patients diagnosed with Tb pass through clearly identifiable stages and statuses on their way to recovery, which is conceptualised as the "patient career". A schematic representation of this patient career is given at the end of the chapter (p. 18). This provides a useful framework for investigating compliance and interpreting the phenomenon from the point of view of patients.

TRENDS IN THE EPIDEMIOLOGY OF TUBERCULOSIS

Tb is endemic in most parts of the world, with the general decline in incidence in highly developed countries being attributed to improved standards of living. The mortality rate has fallen in those countries, due to the introduction of antituberculosis chemotherapeutic agents and B.C.G. immunisation (Essex-Carter, 1979). In spite of advances made, it is a matter of concern when a potentially controllable disease such as Tb remains a problem (Benson and McDevitt, 1980).

Infectivity and Susceptibility:

Tuberculosis is a chronic infectious disease, in which the conflict between the organism, the tubercle bacillus, and the host, is greatly modified by the slowness of the process. The bacillus multiplies only slowly, but on the other hand, is difficult to kill and may remain present and alive in scarred tissue for years. The process of infection follows the following pattern:

An infected person exhales infected droplets, which are inhaled by a disease-free individual. A primary complex develops, consisting of a spot of inflammation developing where bacilli are multiplying, and local lymph nodes become inflamed. Usually, the primary complex heals spontaneously, but in a small proportion of cases progresses to develop as frank tuberculosis anywhere in the body. Others may exhibit an apparently healed primary complex, which then can break down in later life. It is also possible to be re-infected, in which case the reaction of the tissue is much more violent than in an unsensitised person (Burnet and White, 1972).

Susceptibility is affected by genetic constitution, sex, age, socioeconomic conditions, nutrition, and stress. Thus certain ethnic groups appear to have less actual resistance to disease, and it is certainly more widespread amongst the poor, the undernourished, and under conditions of prolonged stress and fatigue (Benenson, 1975; Burnet et al, 1972). A disproportionately high incidence of Tb may therefore be expected in certain ethnic and social groups of society, which has implications for the way in which health care services are offered. Prolonged exposure to infected droplets is a significant factor in susceptibility, putting family and friends of an infected person at highest risk (Essex-Carter, 1979).

Tuberculosis in New Zealand:

There has been a gradual decline in the mortality from Tb in New Zealand, particularly since the Second World War. That decline was attributed to "a full-scale offensive for the eradication of tuberculosis" that was well under way by 1950 (Maclean, 1964, p.375). It involved improved diagnostic and notification procedures, segregation of infected persons, and the deployment of nurses to provide supervision of "tuberculous households". An overall improvement in housing and nutrition was accompanied by education about the causation and spread of Tb.

The fall in mortality rate was not experienced to the same extent amongst the Maori (Maclean, 1964). In the 20 year period 1955-1975, tuberculosis remained the single most important cause of death from infectious causes amongst Maoris, with a rate 5 to 10 times greater than for non Maoris. Possible reasons suggested for the disproportionately high incidence are immunological and social factors, impaired access to health services, and poor compliance with regimens (Pomare, 1980).

There has been a steady increase in numbers of Pacific Islanders immigrating to New Zealand, and the incidence of Tb is now higher in that ethnic group than in any other (Barnett, 1977). Mackay (1972) suggests that the tuberculosis problem is almost identical amongst Pacific Island and New Zealand Polynesians. Both populations seem susceptible to Tb, which may be a racial susceptibility, and it may be related to social and domestic conditions. Barnett (1977) draws attention to the pattern of rural-urban migration that is occurring from both the Islands and rural Maori communities to New Zealand cities, where the stress of a totally different lifestyle added to crowded living conditions may be related to high rates of infection. Prevalence patterns and particular needs of Maoris and Pacific Islanders affect the development of health services delivery in regions where there are large ethnic communities.

Policy relating to the management of Tb as a public health problem has changed along with the trends outlined above. Following the introduction of chemotherapy, less reliance was placed on prolonged rest as the mainstay of treatment, with a result of sanatoria being closed, and Tb patients being treated in general hospitals. Until the early 1970s, the treatment of Tb patients remained the responsibility of the Health Department, and public health nurses were important in the surveillance of patients (N.Z. Medical Journal, 1981). Currently, practically all Tb patients are treated by chest physicians in the same manner as any other hospital out-patient, with a corresponding decrease in the

involvement of the public health nursing service in surveillance. The overall policy of surveillance of Tb patients, as set down in the Public Health Manual (1976), is flexible, and varies with the needs of each health district. Public health nurses retain the responsibility for follow-up of suspected cases of infection and tracing of contacts. They still help supervise Tb patients who are referred by the physician, by periodically visiting them to check on and encourage compliance with the medication regimen. Because a person with inadequately treated Tb is an infection risk to the healthy population, in accordance with the Tuberculosis Act of 1948, the patient does not have the legal right to refuse or discontinue treatment.

The total number of new cases of tuberculosis notified in New Zealand in 1981 was 448 (New Zealand Health Department, 1982).

MANAGEMENT OF TUBERCULOSIS

A health problem becomes a public health problem when the well-being of communities of people is threatened by communicable disease (Benson et al, 1980). Weeks (1977) has indicated that when a proportion of a population is ill with a transmittable disease, it has been up to society to segregate them in order to protect the healthy, and to care for their suffering. This principle has found expression in public health philosophy, and is exemplified in policy regarding Tb management. Although in developed countries Tb is not a major health problem in terms of the proportion of population affected, it is important because of the extent of discomfort and disability associated with it (Benson et al, 1980).

Tuberculosis as a Public Health Problem:

Susceptibility of populations to Tb can be reduced by improving living conditions (including discouraging overcrowding), raising the standard of nutrition, immunisation

with BCG,¹ and the containment of the pool of infection in communities (Benenson, 1975).

The risk of infection is minimised by containment, by which infected persons are identified and treated. There is a wide range of effective regimens now available, usually administered on an ambulatory basis. It is generally accepted that institutional care has no advantage over ambulatory care in treating Tb patients. To a large extent, this is because pharmaceutical isolation has replaced institutional isolation. Containment of the disease as well as treatment of the person depend, however, on adequacy of therapy, and poor therapeutic outcomes are usually the result of irregularity in taking medications (Addington, 1979a; Sbabaro, 1980). Hospitalisation is recommended only to establish the therapeutic regimen, and when the patient is severely ill (Benenson, 1975).

The other principal methods used in tuberculosis control were mass surveillance, by which populations were screened for exposure to Tb, and life-long follow-up of treated Tb patients to ensure that the disease hadn't reactivated. Neither of these are now considered necessary or cost-effective, and mass surveillance is indicated only in high-risk communities. Follow-up of contacts of infected persons is considered a more effective way of uncovering infection in the community, and so controlling the disease (Sbabaro, 1980).

Patients treated on an ambulatory basis are expected to comply not only with the medication regimen, but also with measures recommended to reduce the risk of spread to closer contacts. For instance, they are instructed on covering the mouth and nose when coughing, about careful handling and disposal of sputum, and handwashing and other practices (Benenson, 1975).

By these measures, tuberculosis can be controlled as a

¹ Some degree of protection against tuberculosis is given in the form of the bacillus of Calmette and Guérin (BCG).

public health problem, but effectiveness is dependent on the cooperation of patients.

Treatment of Tuberculosis:

Medication treatment is the keystone of management of tuberculosis. The treatment of Tb is a complex and protracted procedure even though effective drugs are available. The primary agents for therapy are isoniazid, rifampicin, ethambutol, and streptomycin. Because of the propensity of the tubercle bacillus to become resistant, at least two drugs are given concurrently. Side effects of some drugs preclude or limit their use. The selection of the particular agents for concurrent therapy will therefore depend on the sensitivities of the organism, and the tolerance of the patient (Weinstein, 1975).

A "first-line" regimen now widely used is isoniazid and rifampicin concurrently for the duration of the treatment, with the addition of either streptomycin or ethambutol for the first few months. Both rifampicin and isoniazid can produce hepatic side effects, and hypersensitivity reactions. Vitamin B₆ is frequently administered routinely to counteract the neurotoxic effects of isoniazid. Acquired resistance occurs with both drugs, and although primary resistance is still uncommon with rifampicin, the incidence is growing with isoniazid. Ethambutol, the third agent commonly used in the initial stages of treatment, provides a suitable substitute. When resistance or toxicity precludes the use of any of the first-line drugs, reserve drugs are available, in the forms of pyrazinamide and prothionamide. Neither are suitable initially because of their high toxicity, and resistance develops rapidly with pyrazinamide (Kucers and Bennett, 1975).

Weinstein (1975) points out that chemotherapy is necessary, because of the frequently inadequate natural defence mechanisms of the human host. The persistence of the bacilli make a protracted course of treatment necessary, for a minimum of one year. Within the first few weeks of therapy, however, the person improves, with a decrease of cough and fever, gain in

weight, and increased sense of well-being. Problems may arise after this stage as, unless the rationale for prolonged treatment has been explained, the patient may believe treatment is no longer necessary. As the prognosis of Tb and containment depends on the adequacy of medication treatment, there is a need to ensure that therapy is taken regularly for the full duration of the course (Sbabaro, 1980).

Although mortality rates from Tb have fallen in developed countries, the incidence has not declined proportionately, which suggests the continuing importance of the role of infection (Essex-Carter, 1979). Addington (1979b) has identified compliance failure as the most serious obstacle to containment of the disease by controlling the pool of infection. He further suggests that a patient's lifestyle and ability to adhere to a regimen should influence the choice of regimen along with drug sensitivities and tolerance (Addington, 1979a). The health practitioner, therefore, is necessarily concerned with patient compliance with regimens and recommendations, and with ways of enhancing compliance so that treatment goals will be reached, and the disease contained.

PSYCHOSOCIAL IMPLICATIONS OF HAVING TUBERCULOSIS

In an era in which effective antituberculosis agents are available, Tb has become a medical entity, to be dealt with by medical methods. The phenomenalist aspect of having the disease, and attempts by patients to make sense and find meaning in threatening experiences, may be denied or ignored in the clinical context.

The Threat of Having Tuberculosis:

The meaning that illness has from the perspective of the person experiencing it may not coincide with the professional's perception. However, it is the subjective aspect of the illness that significantly influences the behaviour of the patient (Wu, 1973). Herzlich (1973) observes that perception of an illness as "serious" is not a constant classification contingent on such characteristics as pain, and curability, but usually indicates

the accentuation of one feature of the disease. In the case of tuberculosis, usually considered curable, it is its duration that makes it seem serious. Wu (1973) further suggests that the meaning of the illness may be superseded by the significance of the part affected. The heart and blood symbolise life itself, and the act of breathing the experience of being alive. Any impairment of these parts is perceived as extremely threatening, and causes great anxiety. Tb in humans most commonly affects the lungs, which can cause pain, and impairment in breathing, and sometimes haemorrhage will occur. Thus Tb constitutes a threat, the nature of which is hinted at by the popular term of yesteryear, "consumption".

The Stigma of Tuberculosis:

Wu (1973) points out that meanings of illness change as circumstances alter, but there may be a lag, with the result that meanings invested in diseases may be incongruent with current treatment options. Tuberculosis was heavily stigmatised because of an association with poverty and neglect, and as a metaphor for evil. After the tubercle bacillus was identified, years passed before tuberculosis was popularly accepted as a germ-caused disease. Even then, tuberculosis associations such as those in America needed to expend considerable resources in efforts to eradicate the stigmatised image of Tb (Kenen and Schmidt, 1978).

"Stigma" is an important concept in the experience of having Tb, and therefore stigma management concerns patients who feel stigmatised. Goffman (1963) defines as a stigma an attribute that discredits a person's assumed social identity. The critical issue in stigma management is acceptance by others of society. There is a difference between being discredited, when the stigma is known or evident, and discreditable, as in the case of Tb. The stigma is unrecognised by normal people, and the person is faced with the dilemma of whether or not to tell, especially if the risk of being found out is high. Stigmatised persons may expect support from those who are similarly stigmatised, such as

other Tb patients, and from the "wise", such as nurses, whom Goffman describes as normals who are close to and can understand the stigmatised.

Perception of Illness:

Adequate treatment of Tb patients on an ambulatory basis necessitates the cooperation of the patient with the treatment plan, and the ability of the family to maintain its functioning and to support the sick person. The seriousness of the illness for the patient and his family, and the difficulty of the regimen as perceived by the patient, will have a greater bearing on ability to comply with the regimen, than will the practitioner's perceptions.

Herzlich (1973) relates inactivity, as an essential aspect of illness, to the way patients perceive the illness. Thus, illness may be perceived as destructive or as a liberator respectively, in relation to whether the patient resents or welcomes inactivity, or it may be seen as an occupation in that illness becomes an occasion for working towards recovery. The way patients perceive illness has a motivating influence on their behaviour, including compliance.

Illness seldom affects the individual only, but has a disruptive effect in the patient's family. Although an illness may not seem severe to practitioners, yet it may be perceived as serious by the patient, and as such, family structure and functioning is threatened and disrupted. Unless the family adapts, and resolves the crisis, which may be repeated at each delay in recovery or complication, the ability to care for the ill member is likely to be disturbed (Drake, 1973).

The continued importance psychosocial factors have in effectively treating Tb is apparent in that a century after the tubercle bacillus was identified as the causative organism and over three decades after the introduction of chemotherapeutic agents, fresh outbreaks of the disease continue to occur in areas where it is otherwise controlled. Furthermore, the

incidence of drug resistant strains of the organism are increasing. Dubos (1982) asserts that neither immunisation nor medication treatment can control Tb so long as certain social conditions and practices are not taken into account in the management of tuberculosis. He concludes that "we now realise - even more clearly than in the past - that tuberculosis is a social disease" (p.8).

THE CAREER OF THE TUBERCULOSIS PATIENT

When a diagnosis of Tb is confirmed, a person undergoes changes in identity and passes through a series of statuses until he is infection-free and no longer a risk to the healthy population. During this period of time he has particular sets of obligations with which he must comply, and also expectations of health and other services to assist him in doing so, in order to achieve the transition to the desired status.

When a life event has definable stages through which a person passes to reach a definite goal, the concept of "career" may be used (Twaddle and Hessler, 1977). Central to the notion of career is the concept of "status passages", which are definable stages that mark the passage from one identity to the next toward a recognisable end point, or goal.

The identification of the particular stages and status passages, and expected patient behaviour associated with each status, provides a useful framework for investigating compliance, and explaining the phenomenon from the patients' points of view. The career of the tuberculosis patient is presented in diagrammatic form in Fig 1 (p.18).

Identity and Expectations of the Ambulatory Tb Patient:

The focus of the study is from the time the person diagnosed with tuberculosis and established on therapy is discharged from hospital until the course of treatment is complete and he is cured. During this period he is identified as a Tb patient undergoing treatment on an ambulatory basis. He is not considered an infection risk to the community

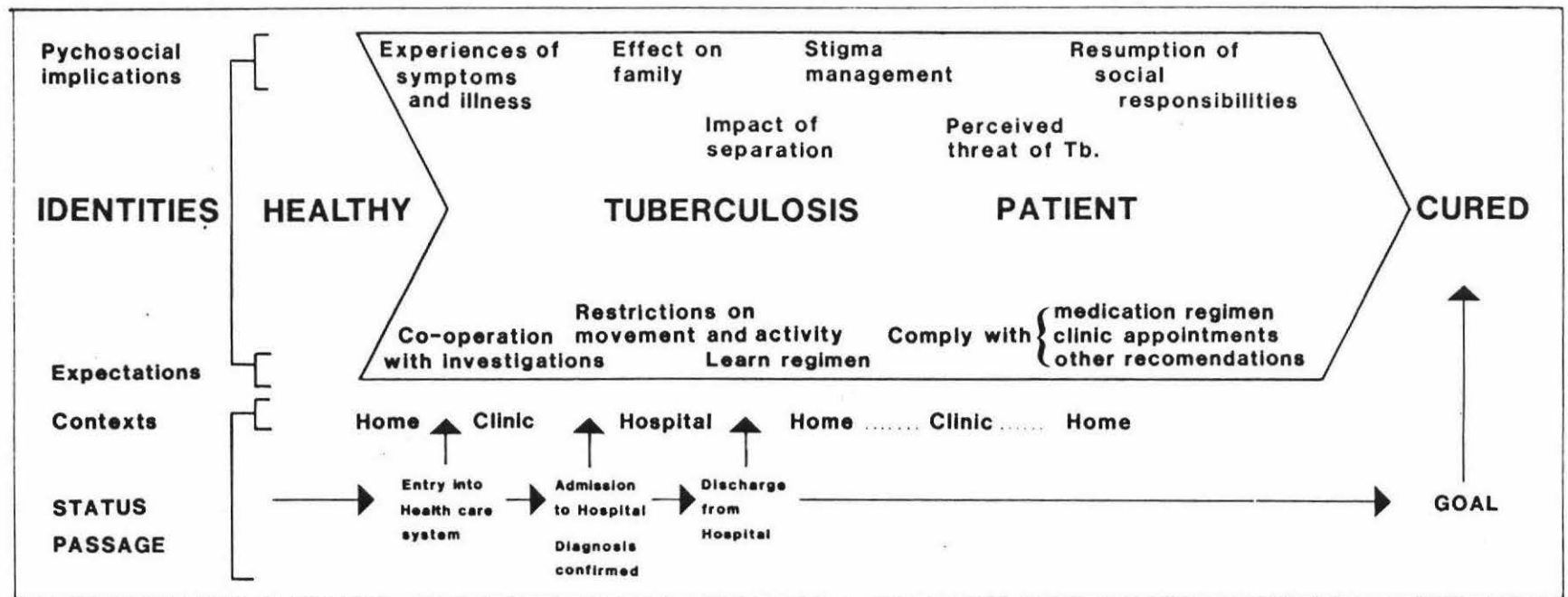


Fig 1: The Career of the Tuberculosis Patient

provided he continues to take medication as prescribed until cessation is authorised by the practitioner,

Being sick implies a change in social identity, which Parsons (1951, 1978) has conceptualised as a social role. The patient has a right to be excused from occupational, family, and other responsibilities and is exempt from being held responsible for his condition. He has two corresponding obligations - he is expected to share a negative value on sickness, which involves a commitment to get well, and therefore he is obliged to cooperate with treatment plans. The role of the ambulatory Tb patient is qualified in that he is not exempt from social responsibilities, but is obligated to comply with therapeutic and other recommendations.

Status Passages:

In the context of Parson's sick-role theory, compliance is seen as the obligation of the patient, and although he is not blamed for contracting the disease, he is held responsible for failure to recover in that it is usually attributed to irregular compliance. Less attention has been paid to the responsibility of practitioners in enabling the patient to successfully manage the change in identity from inpatient to ambulatory patient. Associated with the shift in identity is a change of status and expectations. The hospitalised patient is removed from normal social life and responsibilities, and is cared for by practitioners who are invested with the responsibility for providing treatment. The time of discharge from hospital marks the end of that status and the beginning of a new status, associated with which the patient is totally responsible for caring for himself and for continuing to take treatment as prescribed.

Van Gennep² (1960), amongst the first to describe passages

² Van Gennep published his essay on "Rites de Passage" in 1923, and the English translation was published in 1960.

from one state to another as constants in social life, suggested that there is a need for practices to reduce the harmful effects of these changes. The passage of major changes in status, such as those marking life-cycle crises, have been institutionalised as rites of passage, but the same arrangement underlies temporary changes such as illness. The passage from one discreet identity to the next begins with separation from normal life, is followed by practices to facilitate the transition, and finalised with a resumption of social activities but with changes appropriate to the new status.

Status of the Ambulatory Tb Patient:

After discharge from hospital, the Tb patient resumes responsibility for caring for his basic needs, and is given the responsibility of maintaining medical care.

Orem (1971, 1980) and Verschure (1980) identify self-care as the most prevalent form of caring in society. Basic, or universal self-care behaviours are necessary to survival and health. It follows that when a person is incapacitated from performing his own self-care, another needs to take over the responsibility for doing so if life is to be maintained and health restored. Verschure (1980) distinguishes two possibilities. The more prevalent and important is "cover care", when people close to the sick individual meet his needs. When both self-care and cover-care become inadequate, the institutionalised professional care sector, with its specialised knowledge and techniques, becomes involved.

The present study begins at the point when the extent of involvement of professional caring is being reversed. When patients are discharged from acute care institutions, practitioners are no longer able to meet all the patients' needs for basic and therapeutic care. Moreover, as the patient is not yet cured of tuberculosis, he needs to incorporate into his self-care behaviour what Verschure terms "complementary medical self-care". There is a need for practitioners to educate and support the patient in the

acquisition and performance of these therapeutic self-care behaviours (Orem, 1971). In other words, practitioners have a responsibility for assisting the patient to comply with the treatment plan.

The change in status for the patient that is marked by discharge from hospital also signifies a resumption of cover-care behaviour by members of the patient's family, which have been suspended or greatly reduced during the patient's hospitalisation. If "professional care" practitioners do not recognise the extent of involvement of the family and others providing cover-care, supportive and educative services to prepare for the transition in caring may be inadequate or misplaced.

SUMMARY

The knowledge and technology for controlling and even eradicating tuberculosis in man are available. What was once regarded as a serious infectious disease that carried an uncertain and often poor prognosis is now considered curable provided chemotherapy is taken as prescribed over a relatively protracted period of time. Failure to comply with the therapeutic regimen has been identified as the major barrier to achieving control of Tb as a public health problem. Incongruence between the medical perspective on Tb and psychosocial implications of the disease have contributed to breakdowns in achieving control. The issue of improving compliance with health care plans is of major importance when Tb patients are treated for the most part on an ambulatory basis, and assumes urgency as the incidence of drug resistant strains of the bacillus increases.

The concept of patient career provides a useful framework for investigating patient compliance phenomenologically with a view to improving compliance as therapeutic self-care behaviour. The stage of the patient career in which compliance is critical is seen in relation to other stages, as well as to the status passage necessary to facilitate the transition from being cared for by professionals to resuming responsibility for one's own care. Compliance with the

treatment plan is thereby considered to be a form of therapeutic care complementary to basic self-care, and strategies by practitioners to improve compliance conceptualised as practices associated with the status passage, and oriented toward linking self-care and cover-care.

CHAPTER THREE

REVIEW OF LITERATURE ABOUT COMPLIANCE

Awareness of the phenomenon of noncompliance is not new to the twentieth century. Hippocrates is quoted as having said:

The physician should keep aware of the fact
that patients often lie when they state they
have taken certain medicines. (Haynes, 1979a, p.3).

Since the 1960s there has been a considerable increase in the literature related to compliance, indicating a growing awareness of the phenomenon and its implications (Dunbar, 1979). That interest coincides with the trend toward long-term management of chronic sickness on an ambulatory basis (Marston, 1970). Although practitioners over several decades have been concerned about patient compliance, indications are that considerable frustration still exists in finding practical answers to the problem (Sackett, 1976b).

The current state of knowledge about patient compliance is presented by means of reviewing recent literature, in particular nursing literature, in this field. The problem of noncompliance is considered first in relation to the treatment of tuberculosis, and then in respect to health care generally. Methods of measuring compliance are discussed, and the incidence of noncompliance reported.

The research emphases have been on the one hand, to identify determinants and predictors of noncompliance, and on the other, to develop strategies for improving compliance. Accompanying recent developments in health care, the relationship of the patient to practitioners has changed, and compliance has come to mean more than adherence to prescribed medications. Findings of research focusing on these emphases and trends are discussed.

The review concludes with a consideration of the patient's perspective on compliance.

Meaning of the Term "Compliance":

Compliance is the term most widely used to describe the extent to which patients' behaviour coincides with medical prescriptions and instructions, and also with advice about health care (Sackett, 1976a). The fact that patient compliance is a behaviour that occurs for the most part outside of the clinical setting raises questions about the appropriateness of the term. Objections are generally rooted in the changing relationship between society and health professionals, and to the appropriateness of the dictionary definition of the word in that context. For example, the Webster dictionary (1975) defines "compliance" as:

"complying with a demand or an order;
an acquiescing or yielding; a
disposition to yield to others."

Yoos (1981) considers that the inherent nature of man is more self-determining than acquiescing. Because of those connotations, there has been persistent criticism of the use of the term. It is seen as a judgemental concept, with the patient being judged by standards and criteria set by practitioners (Caplan, 1979). By implication, failure lies with the patient, whereas in fact practitioner behaviour is critical, and therefore the term skews the phenomenon (Jonsen, 1979). "Patient co-operation" is proposed as a more appropriate term (Eisenberg, 1980). Barofsky, Sugarbaker, and Mills (1979) accept that "compliance" accurately describes the relationship at one end of the continuum, but argue that there ought to be movement along the continuum. "Adherence" describes a situation where both parties adhere to a set standard, and "therapeutic alliance" when decisions are being made through a negotiative process.

Sackett (1976a) considered these amongst several alternative terms, but discarded "adherence" as having similar connotations to compliance, and rejected "therapeutic alliance" as being too cumbersome. Therefore, "compliance" was retained for utilitarian reasons, in view of the fact that the term is widely used and understood. The inferences of the term on

those grounds were felt to outweigh the disadvantages of the negative connotations (Haynes, 1979a).

For the purposes of the present study, the term "compliance" is retained not only for reasons of utility and economy, but because it is an appropriate term in the context of Tb management. Where the practitioner has a legal mandate for ensuring adequacy and completion of treatment, patient compliance is literally the desired behaviour.

THE PROBLEM OF NONCOMPLIANCE

Research undertaken in recent years has given rise to a great deal of descriptive data about compliance, some actually predictive of behaviour, but it is asserted that little exists that is useful in intervening in the problem of noncompliance (Addington, 1979b).

Early Contributions to Compliance Literature:

In recent times, historically concern about patient compliance developed first amongst tuberculosis specialists, and then amongst psychiatrists (Haynes, 1979a). Both groups are charged with protecting the public from the threat of potentially dangerous persons, be the risk from infection or disruptive behaviour. If volitional compliance cannot be accomplished, both have authority to resort to coercive measures, in the form of institutionalisation, and direct supervision with administration of therapy (Baekland and Lundwall, 1975; Haynes, 1979a). The literature suggests that in these, and other contexts of long-term therapy of chronic disease where poor compliance remains a problem, practitioners continue to experience frustrations and feelings of powerlessness.

Compliance failure amongst tuberculosis patients

obstructs control of the disease. It needs to be overcome by removing as many barriers to compliance as possible (Addington, 1979a). To achieve this is not always straightforward, as barriers can be difficult to identify. Strauss (1975) points out that people who feel

Tb is stigmatising may deny they have the disease and refuse to submit to the regimen, or for fear of discovery may not carry out more visible aspects of a regimen.

In discussing compliance of Tb patients, Dudley (1979) suggests that there is a tendency for people to rebel against authority. Here, compliance failure is regarded as a manifestation of patients rejecting competent medical advice because of its orthodoxy. In the opinion of Addington (1979b), noncompliance is a form of self-destructive behaviour, to which the only possible solution, if the public are to be protected from infection, is direct supervision of therapy. However, although the concept of supervised treatment is simple, it is difficult to accomplish as both staff and patients quickly tire of a demanding programme (Sbabaro, 1980). This became evident in a trial of supervising the treatment of Tb patients with a history of compliance failure (McDonald, Memon, and Reichman, 1982). Moreover, when the system of supervised treatment was terminated and self-administration resumed, compliance returned to base-line levels.

Hecht (1974) reported that serious medication error amongst ambulatory Tb patients was reduced from 53 percent (in the control group) to 17 percent in the experimental group as a result of teaching and counselling by nurses. Education of patients while in hospital and with subsequent reinforcement at outpatient clinics and at home was recommended as a way of improving compliance. Sbabaro (1979) draws attention to the potential in a supportive practitioner-patient relationship to assist compliance with a protracted treatment, in which concern for the patient's health and person in the context of the family is expressed and maintained. He goes on to say that those involved in the treatment of Tb not only ought, but must, concern themselves with patient compliance if the obligation to control the disease by ensuring adequate treatment is to be satisfied.

Present State of Knowledge of Compliance - A Summary:

During the early 1970s, Sackett and Haynes (1976) exhaustively researched literature on the topic of compliance. At that time, a critical review of 185 independent original articles on compliance led to the conclusion that there was no single or simple explanation of the phenomenon, making it difficult to predict or to design interventions. Since that review, there has been an explosion of scientific articles on compliance, so that Haynes (1979a) now states that it is no longer possible for the team to evaluate each report as previously.

Factors relating to compliance which emerged from the review are summarised as follows (Haynes, 1976).

Demographic characteristics of patients - negative relationship.
 Features of the disease - negative relationship.
 Features of the regimen - there is an inverse relationship between complexity and duration of the regimen (high) and level of compliance (low).

Features of the therapeutic source - continuity of care, extended patient supervision, and patient satisfaction with the practitioner, are positively related to compliance.

Sociobehavioural characteristics of patients - many characteristics can be incorporated in the Health Belief Model. It is useful in predicting compliance, but many features of the model are relatively enduring and difficult to modify. Other socio-behavioural features to receive attention include those to do with family, and level of education. Compliance is enhanced when the patient's family is stable and supportive. There is little demonstrable relationship between educational achievement, intelligence, and knowledge about the illness and treatment, and compliance.

Referring to the above review by Sackett et al, Cohen (1979) noted that few consistent patterns or principles emerged, even when only methodologically excellent studies were included. It is posited that the paucity of generalisable findings can be attributed to the complexity of the phenomenon which although taking place for the most part in domestic environments, has

been investigated mainly in clinical contexts.

Experiences in health care services indicate that compliance levels fall in relation to the extent of on-going behaviour change required of persons. For instance, the effectiveness of large-scale public health programmes has been markedly superior when the goal can be achieved at source than when active on-going changes of living habits are required (e.g. pasteurising milk at treatment plants rather than domestic boiling of milk to control bovine Tb) (Kelley, 1979). Compliance with prescriptive recommendations, when a new behaviour is added, is higher than that with proscriptive recommendations, when persons are advised to eliminate habits or modify behaviour (Marston, 1970).

It has been pointed out that both groups, practitioners and patients, are intimately involved in the decision-making process. The practitioner makes decisions in relation to the diagnosis and associates prescriptions and recommendations. Thereafter, it is no longer the practitioner who makes decisions, but it is the patient who decides whether or not, and to what extent, to comply with recommendations. To do so correctly and appropriately, the patient needs to be motivated and have necessary knowledge (Rosenberg, 1979).

Consequences of Compliance Failure:

The phenomenon of patient compliance has profound consequences for therapeutic outcomes for individuals; for the development of knowledge in medical and health sciences; for the control of disease in populations; and for society's health bill (Becker, 1979; Dunbar, 1979).

With the antibiotic era bringing dramatic successes in the treatment of common infectious diseases of hitherto unpredictable outcome, the patient came to be seen as a passive recipient of prescribed treatment. Increasingly, with a preponderance of chronic disorders in aging populations, patients need to be active participants in their own treatment plans.

In such conditions, even effective therapeutic regimens will not of themselves accomplish treatment goals unless the patient complies with therapy over prolonged periods of time, and sometimes for life. Increasing attention is moreover being given to the need for cooperation with modifications of lifestyle, in order to delay the onset of degenerative processes (Clark, 1979).

Noncompliance in these contexts threatens the success of preventive or therapeutic regimens by interfering with potential benefits. It is a major cause of treatment failure, and may unnecessarily involve the patient in further diagnostic tests and more powerful regimens which, as well as being costly, can have iatrogenic effects. Poor therapeutic outcomes because of noncompliance can give rise to dissatisfaction with the service and the practitioner (Becker, 1979).

The compliance factor makes it difficult for practitioners to accurately evaluate the therapeutic efficacy of a regimen, a situation that has consequences not only for individual patients, but also for the advance of knowledge about treatments. Attrition and poor compliance confound the results of controlled clinical trials (Dunbar, 1977).

Barofsky et al (1979) suggest that a person's right to make decisions about matters affecting himself and his lifestyle includes the right to decide whether or not to adhere to the regimen. However, courses of antibiotics that are irregularly administered or not completed result in the evolution of resistant strains of micro-organisms. Poor compliance of individuals thereby affects not only themselves, but populations. When long term treatment is necessary, as in the micobacterial diseases (Tb and leprosy) the problem is critical, and resistance to available drugs is a growing problem globally (Lang, 1980; Smith, 1976).

Finally, noncompliance is wasteful of human and monetary resources, and is a major contributor to the costly problem of drug wastage (Potter, 1981).

Issues in the Measurement of Compliance:

Comparability of reported rates of compliance is limited by the very considerable variation in the way compliance is defined - e.g. as precisely coinciding with the prescription, or as adequate to achieve treatment goals - and the method of measurement (Roth, 1979). There is no ideal method, and the choice of instrument(s) will depend on the reasons for collecting data and the context in which the investigation takes place (Dunbar, 1979). For instance, the issue of whether measurement is being carried out for research purposes or as part of a health care programme will influence the choice of method and precision of measurement (Gordis, 1976).

Compliance with medication can be measured directly or indirectly. Direct measures include analysing the drug in serum and urine. Advantages of objectivity are outweighed by problems such as the wide individual variation in physiological metabolism of drugs. There are difficulties in random or surprise sampling (without which compliance patterns may not be detected) and problems of ethics and cost associated with intrusive measures (Dunbar, 1979; Gordis, 1979).

Amongst indirect measures, pill counts provide a simple and inexpensive method, requiring that inaccuracy in dispensing be ascertained and that arrangements are made for the collection and reissue of medication containers. Because no information is provided about who takes the pills and when, the method cannot stand alone as an instrument (Dunbar, 1979; Gordis, 1979).

Ratings of patient compliance by practitioners is inaccurate and unreliable, with a tendency for each practitioner to assume that his own patients comply. Likewise, patients' self-reported compliance behaviour is misleading, with patients tending to under-report poor compliance and overrate good compliance (Dunbar, 1979). A longitudinal experimental study found a low correlation coefficient between both patient statement of compliance and pill counts, and physician estimate of patient compliance, and pill counts. In both cases, the

subjective assessment of compliance was far higher than that indicated objectively by the use of pill counts (Roth, 1979).

Dunbar (1979) and Gordis (1979) suggest that therapeutic outcome should not be used to assess compliance, as that may be affected by a number of intervening variables, both physiological and social.

There is agreement that compliance is most usefully and accurately assessed by the use of multiple measures, with objective measures, whether direct or indirect, being filled out with qualitative data (Dunbar, 1979). An instrument which simply measures the amount of medication taken or not would be unable to distinguish between the form and intent of the behaviour, for example, and would therefore be limited in interpreting the nature of the phenomenon.

For instance, a broad distinction has been made between volitional noncompliance and error (Kellaway and McCrae, 1975). Compliance can also be circumstantial, due to unanticipated or unavoidable intervening circumstances (Gill, Fairbrother, and Cullen, 1981). Another classification distinguished between noncompliance by omission (not taking prescribed drugs) or commission (taking drugs that hadn't been prescribed), and scheduling error (taking prescribed medication at the wrong times, due to misunderstanding or deliberate nonadherence) (Hulka, Cassel, Kupper, and Burdette, 1976).

Assessing compliance qualitatively has been neglected largely, and devalued as "subjective" and "soft" data. However, compliance is a subjective phenomenon, and takes place in circumstances that make direct observation by an investigator extremely difficult. An account of what the patient has done, including why and how he did so, can best be obtained from the patient directly, and requires a method of assessment that relies on a well-developed interview technique and the skill of the interviewer to elicit and verify information (Feinstein, 1976).

Magnitude of the Problem of Noncompliance:

Indications in the literature are that one third or more of all patients fail to comply with prescribed regimens. It is compliance with medication regimens that has been measured most frequently. Dunbar (1977) reports that a range of between 33 and 82 percent of patients err in taking medications. The way compliance with medication regimens is operationalised and measured has a bearing on reported rates. Sackett (1976a) has suggested that concern with compliance needs to be related to treatment goals. It is unnecessary to improve compliance beyond a certain level, e.g. 80 percent of the time, if present levels of compliance are not detrimental and therapeutic goals are already being achieved. Hence, in some studies a distinction is made between overall compliance failure and the proportion that is serious. Hecht (1974) reported that 68 percent of Tb patients erred in taking medication, 53 percent of which were serious. Of a sample of 178 geriatric patients, 41 percent made no error at all, and of the 59 percent of compliance failure reported, 26 percent were classified as serious (Schwartz, Wang, Zeitz, and Goss, 1962).

Unusually high compliance rates amongst 3,800 out-patients were reported (Berkowitz, Malone, Klein, and Eaton, 1963). These ranged from 69 percent with restrictive recommendations, 76 percent with medication regimens, to 86 percent with return clinic appointments. However, assessment relied completely on physicians' responses to a questionnaire, which method, according to Roth (1979) tends to overestimate compliance. Findings of the study demonstrate, though, that the particular prescription or recommendation with which the patient is expected to comply will give rise to variation in reported rates of compliance. Sackett (1976b) has summarised reported rates of compliance in the following areas:

- Compliance with medication regimens: With those prescribed for short periods of time, a large variation is shown, and a decline in compliance from one day to the next may be demonstrated. A large variation of compliance with prolonged courses of treatment is also evident, with an average rate of 54 percent.

- Compliance with clinic appointments: Eighty-one percent of sick patients will comply, and 47 percent of asymptomatic or cured patients will do so.
- Compliance with diet and other restrictive recommendations: The only comment was that few studies existed, as the emphasis has been on compliance with medication regimens.

The few investigations that have been conducted in New Zealand indicate similar patterns. In a study of 315 patients discharged from medical wards, it was found that 40 percent complied poorly with medication regimens, some by intent, but others because instructions were misunderstood. Of the remainder, a further 13 percent were taking medication incorrectly because the prescription was either written or filled incorrectly (Kellaway and McCrae, 1975). In relation to attendance at clinic appointments, a 46 percent failure rate occurred in a sample of 210 paediatric out-patients (Kellaway and Brown, 1980). Lang (1980) observed a similar attrition rate in a small survey of 45 leprosy patients.

It is evident that noncompliance is more pervasive than has been previously recognised by practitioners, suggests Clark (1979), and therefore there is a need to develop ways of improving compliance.

DETERMINANTS AND PREDICTORS OF NONCOMPLIANCE

Much research effort has been directed at finding relationships between characteristics of the patient and compliance, in order to recognise patients at risk of compliance failure so that appropriate measures may be taken (Blackwell, 1973). Those efforts have failed to provide clear and consistent patterns of compliance behaviour. There is a multiplicity of findings that are not consistent and at times are contradictory, and which therefore fail to be predictive of compliance (Becker, 1976). There have been attempts by Blackwell (1973) and by Baekland et al (1975) to identify clusters of factors that are associated with noncompliance, based on the assumptions that

although it isn't possible to predict a "noncomplier", it is possible to avert noncompliance by recognition of associated constellations of variables. Such factors are those to do with the patient, with the regimen, with the health care service, and with the environment.

The earlier and more common approach to the study of compliance focused on identifiable demographic characteristics of the patient, and at a similarly concrete level, features of the illness and regimen. A more dynamic view of the patient is implicit in the sociobehavioural models that have been developed, and which provide bases for the development of strategies to improve compliance.

Demographic Characteristics of Patients as a Factor in Compliance:

Based on assumptions that noncompliant patients would share particular characteristics, easily identifiable and quantifiable variables, such as age, sex, ethnicity, and socioeconomic factors, have received attention (Svarstad, 1976). A large proportion of studies have documented the relationship of such factors to compliance, even when to do so is not the focus of enquiry. Marston (1970), Svarstad (1976) and Becker (1979), who reviewed 86, 84, and 176 articles respectively, agree in their conclusions concerning the following characteristics:

Age: Extremes of age seem to be associated with low compliance rates, probably because the very young are resistant to taking unpleasant medicines, and the elderly forget or neglect the regimen. Findings in relation to other age groups are inconclusive.

Sex, marital status, religion, and ethnicity: No consistent relationship has been demonstrated between any of these factors, and compliance.

Socioeconomic status (including income, educational level, and occupation): Where an association has been indicated, the issue seems to be one of access to services and information.

Personality: No relationship can be supported. Traits that have been included are intelligence, authoritarianism and dependency, anxiety, defensiveness, internalisation, psychopathy, and others. Personality inventory scores, thematic apperception test scores, and other methods of measuring personality have not been useful in predicting compliance behaviour, and attempts to relate body image and self-concept with compliance have had similarly inconclusive results.

The adequacy of the sociodemographic approach can be questioned for several reasons. Even if consistent relationships could be demonstrated, demographic and personality characteristics are largely immutable, and do not suggest appropriate interventions (Becker, 1979). Patients believed likely to comply on the basis of personal characteristics may fail to do so, while others will comply under the most adverse of circumstances. Furthermore, there is evidence that an individual's behaviour will vary over time, in different contexts, and in response to different forms of advice and different practitioners (Svarstad, 1976).

Becker (1976) attributes the inconsistency of findings to the use of the medical model to explain a social phenomenon. Commonsense explanations for compliance failure can thereby be obscured. For example, studies in nursing by Windstrom (1975) and Mealey (1977) amongst ethnic minorities in America noted such factors as distance from clinics, infrequency or cost of transport, and lack of childminding facilities, as reasons for nonarrival at clinics.

The Illness and the Regimen as Affecting Compliance:

In a critical review of studies concerned with the relationship of the disease and compliance, few associations emerged between diagnostic label, nor even severity of disease, and compliance (Sackett and Haynes, 1976). Compliance tended to be lower amongst those with schizophrenia and other personality disorders, but the association is not invariable.

For example, in a study in nursing (Giberson and Larson, 1981), 117 patients discharged from a psychiatric unit were interviewed, in which it was found that neither diagnosis nor regimen were related to compliance.

Commonly, the presence of symptoms is a factor positively associated with compliance both with taking medication that provides relief, and with keeping clinic appointments (Sackett, 1976b). On the other hand, in a study of patients with glaucoma, Vincent (1971) found that if expectations for treatment weren't being met and symptoms persisted, levels of compliance with eye-drop treatment fell.

The nature of the regimen itself is much more predictive of compliance. Fitzgerald (1976) has suggested that the explanation of between 25 and 60 percent of compliance failure may lie not with the patient, but with the regimen. Contrary to expectations, the occurrence of side effects does not have a negative effect on compliance unless they are very severe. Whether or not the type or form of medication has an effect is uncertain.

It has been established, however, that the following factors have a definite negative relationship with compliance:

Frequency: the more often medication needs to be taken, the poorer is compliance.

Complexity: the greater the number of drugs taken concurrently, and the more complex the regimen, the lower the rate of compliance.

Duration: the more prolonged the treatment, and the more time has lapsed since it was commenced, the lower the rate of compliance.

In some instances, it is theoretically possible to improve compliance by simplifying and otherwise modifying the regimen (Fitzgerald, 1976). Sackett (1979) has drawn attention

to possibilities of doing so at source, by the manufacture of long-acting or compound drugs, and by attention to packaging. The cost of doing so, together with variations of patients' specific needs and metabolism place limitations on that approach, but the principle of modifying the regimen provides the basis for certain strategies to enhance compliance.

Sociobehavioural Characteristics of Patients in Relation to Compliance:

Approaches that emphasise identifiable factors to do with the patient, the illness, or the regimen can be criticised because of the static view of compliance implied. Amongst models that have been developed that take a more active view of the patient and his motivation as well as ability to comply, are the Health Belief Model, Locus of Control, and family and social support theories.

The Health Belief Model (abbreviated H.B.M.) was initially developed to explain and predict preventive health behaviour, and has been adapted to explain compliance as part of sick role behaviour (Becker, 1976).

Compliance is operationalised as a process involving both cognitive elements and subsequent behaviours (Becker, Drachman, and Kirscht, 1974). The likelihood of compliance is postulated as being an outcome of the perceived threat of the disease and potential benefits of treatment (a combination of beliefs, attitudes, and knowledge), which is modified by factors that constitute facilitators and barriers. The factors include context and quality of care, patient-practitioner interaction, and features of the regimen. On the basis of a demonstrated congruence between beliefs and behaviour, and the significance of moderating variables, it should be possible to construct a relatively simple questionnaire in the form of a "compliance history", so that potential problems can be identified and interventions implemented (Matthews and

Hingson, 1977). A reported example in practice used the H.B.M. in combination with social support theory as a basis for assisting patients with hypertension to adhere to prescribed therapy (Foster and Kousch, 1978).

A considerable volume of research has been generated using the H.B.M., by which definite relationships between cognitive and behavioural relationships have been demonstrated. Becker (1979) cites 29 original studies using one or more variable of the H.B.M., 18 of them concerned with preventive health recommendations, and the remainder to do with therapeutic regimens. Although most studies supported aspects of the model, there were some negative findings.

Articles in recent nursing literature that have reported investigations into the association of health beliefs and compliance have failed to support a positive relationship. Stillman (1977) used the H.B.M. to investigate compliance with Breast Self-Examination, and findings indicated that although 97 percent scored high in perceived susceptibility, only 40 percent practised monthly Breast Self-Examination as recommended. It was not possible therefore to state that beliefs cause or predict behaviour. In a sample of 71 patients with hypertension, Andreoli (1981) investigated differences between compliant and noncompliant patients, as assessed by clinical progress. In the study no difference was found between the two groups in their health beliefs, and self-concept, and compliance behaviour. A weak and inconclusive relationship was found between health beliefs and knowledge, and compliance with an exercise rehabilitative programme for patients who had undergone open heart surgery (Tirrell and Hart, 1980). The variable that was most strongly related to the very low level of compliance observed amongst the 30 patients was the perception of barriers, but the conclusions from the study can be questioned because of the rigid operationalisation of compliance.

Taylor (1979) included 128 patients with hypertension in a study based on the assumptions implicit in the H.B.M. It was found that beliefs ascertained at the beginning of the study did not predict compliance six and twelve months later. Furthermore, it became evident that beliefs developed along with compliance behaviour as a result of experience with treatment, rather than preceded or determined behaviour. Conclusions were that a routine enquiry into health beliefs at the outset would be unlikely to be helpful in improving compliance.

Locus of Control: The other sociobehavioural theory that has received considerable attention in attempting to explain and modify compliance is the Locus of Control model. The model is based on social learning theory, and has been broadened to associate behaviour with the extent to which people believe they control events (Becker, 1979). It is postulated that those with an internal locus of control, who believe that they have control over events, will be more motivated to master health information, better able to influence and negotiate with health personnel, and as a result will be more co-operative with the treatment (Arakelian, 1980). People with an external locus of control, on the other hand, feel powerless to do anything about a situation they believe is controlled by outside forces or persons, and therefore are less motivated to participate.

Findings of studies reviewed (Becker, 1979) indicate that feelings of control over life in general, and health in particular are positively related to compliance with proscriptive recommendations, preventive action, and medication regimens. In a recent nursing study, however, the positive relationship between locus of control and compliance was not supported. Using past compliance with immunisations as the criterion, a randomly selected sample of 94 mothers were sorted into

compliant and noncompliant groups. Their locus of control, value on health, and perceived vulnerability to the diseases were investigated by means of a standardised interview schedule, and no significant differences between the groups were demonstrated (Rosebluum, Stone, and Skipper, 1981).

On the basis of major tenets of the model described above, Arakelian (1980) proposes that the Locus of Control model is potentially useful in modifying compliance. However, limitations are that techniques proposed are specialised behavioural techniques, and so are of limited applicability for practitioners not familiar with the theory or without sufficient time to effectively implement strategies. Furthermore, locus of control exerts its most profound influence in novel or ambiguous situations, and therefore utilisation in familiar health situations or chronic illness contexts is inappropriate.

The locus of control theory, like the H.B.M., has received attention because of the potential to identify factors that motivate compliance. However, a criticism of the sociobehavioural approach is that it contains an implicit bias in emphasising patients' characteristics to the neglect of other elements in the patients' situation (Svarstad, 1976).

Family and Social Support: Although earlier research on compliance neglected the potential of the family, it is becoming apparent that the more prolonged the regimen and the more extensive the behaviour change required, the more important family and social support becomes (Becker, 1979). Some patients are dependent on their family for the initiation and continuation of treatment, particularly the disabled, elderly, or children. Most of what is documented about the role of the family is in the context of the effect mothers have on their children's compliance with regimens. The

influence of the family on non-dependent members is acknowledged but not documented, particularly as their attitudes and beliefs about the sick role and the treatment can bring pressure to bear on the patient to conform or not (Becker and Green, 1975).

The positive effect that social support within the family has on patient compliance has been observed in a number of nursing studies. Vincent (1970) attributed a higher compliance rate amongst men to the factor that wives were more supportive than husbands. Psychiatric patients who were married were significantly more likely to comply with out-patient appointments than those who were not married (Giberson et al, 1981). Foster et al (1978) developed an effective assessment and counselling approach to assisting hypertensive patients to adhere to the treatment plan. An underlying assumption was that social support is needed for health action which needs to be sustained over a long period of time.

STRATEGIES FOR IMPROVING COMPLIANCE

Ozuna (1981) suggests that a more promising approach to the study of compliance is by experimenting with interventions designed to improve compliance, rather than continue searching for predictors and new relationships. Even though sociobehavioural models provide a dynamic perspective on compliance, it is not always possible to alter factors that are identified, and so the objective of improving compliance remains unrealised. Sackett (1979) claims that enough is now known about compliance to enable practitioners to identify and improve poor compliance.

A range of strategies have been suggested, many of them arising from the known associations between compliance and the regimen, health beliefs, and satisfaction with care. Matthews et al (1977) suggest that as a person's beliefs, situation, and needs

change over time, there is a need for on-going evaluation of the basis on which the strategy was developed, as well as the strategy itself. Sackett (1976a) warns of the problems of practitioners adapting principles that are poorly understood from other disciplines. Furthermore, before embarking on any strategy to improve compliance, it should be known that the diagnosis is correct, and the therapy known to be effective with benefits outweighing potential side effects. Having ascertained that the treatment is necessary, then services to assist the patient to adhere to the regimen are as essential as diagnosing and prescribing, and in fact it is the professional and ethical responsibility of the practitioner to do so (Jonsen, 1979).

Haynes (1979b) critically reviewed all studies that reported the testing of an intervention designed to improve compliance, with success rate of strategies as follows:

- Educational strategies : 50 percent success rate
- Behavioural strategies : 82 percent success rate
- Combined strategies : 75 percent success rate

It was concluded that noncompliance is seldom because of lack of knowledge, and that effectiveness of educational strategies is due more to the "attention placebo" effect than the educational content. The author draws attention to the universal finding that compliance drops to baseline levels when the strategy is discontinued, which provides further support for the conclusion that the "attention placebo" is probably the most significant element in all strategies.

Educational and Counselling Strategies:

The effectiveness of educational strategies has yet to be validated, but Rosenberg (1979) asserts that there is a place for perseverance in that the patient not only needs to know, but has a right to information, so that he can make correct decisions regarding adherence.

Strategies that did not result in behaviour change were "fixed content" health messages, lecture-demonstration series, and programmed instruction. Individual counselling, counselling plus instruction, and role-playing improved compliance during the programme, but changes were not maintained (Haynes, 1979b).

Redman (1980) suggests that the acquisition of knowledge does not itself motivate nor assist the patient in developing coping behaviour, hence the weakness of strategies that give information, but are not developed within an educational model.

Education of patients by nurses is advocated as a basis for improving compliance in practice settings (Conway-Rutkowski, 1982) and has been utilised, for example, in an approach reported (Romankiewicz, Gotz, Capelli, and Carlin, 1978). There are a number of recent studies that have tested educational strategies, in many of which nurses are key personnel in the intervention.

Positive results of educational strategies on patient compliance have been reported by Hecht (1974) and Hulka et al (1976) in which knowledge about the regimen is positively related to compliance. In a study by Kellaway and McCrae (1979) noncompliance, both intentional and by error, was reduced by about 40 percent through patient education and counselling, but the intervention had no effect if the patient felt that the regimen was unnecessary. From the results of a study using an immigrant population, in which the attention variable was controlled, it was inferred that the educational content of the strategy effectively improved compliance (Aslam, Davis, and Fletcher, 1979). This conclusion is in contrast to findings of a study in which compliance of patients who received education plus attention was no greater than that of a control group who received attention only, but both groups were more compliant than the general clinic population (Spector, McGrath, Uretsky, Newman, and Cohen, 1978). A significant difference between the study population is that poor fluency in English amongst immigrants (in the study of Aslam et al), constituted a major barrier to access of information. It is argued that where there is no barrier of access to information or lack of knowledge, then the attention factor becomes the significant variable in promoting compliance.

Controlled studies conducted by Lowe (1970) and Bille (1976) failed to demonstrate that patient teaching (utilising

a structured programme) improved compliance. Bille also investigated one aspect of body-image, "body cathexis", and demonstrated a significant relationship with compliance, but no relationship between body-image and readiness to learn.

In a study amongst 192 black males of lower socio-economic levels, it was found that educational interventions by nurses not only did not improve patient compliance, but that education tended to result in earlier withdrawal of patients with chronic diseases from clinics (Tagliacozzo, Luskin, Lashof, and Ima, 1974). The researchers suggest that a preoccupation with the consequences of the intervention for compliance can mask other significant outcomes. For instance, it is inferred that education enhanced competence of patients and confidence in self-care, that resulted in withdrawal from clinic supervision. Interventions also tended to legitimise the unburdening of anxieties and concerns on the part of the patients, which was regarded as a positive outcome. In a longitudinal study by Roth (1979), in which patient teaching was employed, it was found that even though compliance remained poor, the rationale of treatment was better understood, which helped reduce fear.

Neufield (1976) draws attention to the fact that although educational strategies are evaluated on the basis of outcome for compliance, they can be faulted on educational principles. Five learning principles that have been developed as criteria for evaluating patient education are individualisation, feedback, relevance, understanding of objectives, and motivation, but these seldom receive mention in reports of educational strategies.

Behavioural Strategies:

Barofsky (1976) suggests that past experiences with illness and drugs, and interactions within the health care system can have a major influence on current compliance behaviour. As such, compliance is a learned behaviour, and

because patients may be unable to understand or articulate the reasons for their behaviour, teaching strategies are of limited effectiveness,

Consistent with the premise that compliance is a learned behaviour, a strategy has been developed by which patients in hospital administer their own medications. In this way, a sense of responsibility develops along with a habit of taking medication, and the extent of behaviour change associated with discharge is reduced (Gill et al, 1981; Kellaway et al, 1975).

Simple behavioural strategies include the development of reminder devices, ritualising regimens, and involving household members in the strategy (Haynes, 1979b). Specialised behaviour modification techniques that could be employed include differential reinforcement, extinction, modelling, desensitisation, self-control, self-monitoring, and mastery learning. These are, however, time-consuming, and require the on-going attention of the practitioner (Barofsky, 1976).

A technique that has been used with some success in the management of certain chronic disorders such as hypertension, is regimen tailoring. Patients are taught to monitor the disease, to tailor the regimen with signs and with daily living, and to assume responsibility for self-recording and reporting (Foster and Kouch, 1980; Weintraub, 1975). Hoepful-Harris (1980) describes the use of reward and reinforcement to assist patients in complying with an exercise rehabilitative programme.

Strategies discussed so far assume that the practitioner retains responsibility for formulating the treatment plan and assisting the patient to accept and adhere to it. Barofsky et al (1979) describe a system of enhancing adequacy of treatment through "patient contract", or "therapeutic alliance". Through negotiating and bargaining, the regimen rationale is clarified, the patient's reservations and anxieties verbalised, and a mutually acceptable therapeutic plan developed. It needs

to be recognised, though, that this form of behavioural modification is not suitable for use in the treatment of all diseases.

Strategies Concerned with the "Health Care Service":

Conclusions by Haynes (1979b), and others, that compliance falls to baseline levels when strategies are removed suggest that changes in the context and manner in which care is given is potentially a more enduring approach for improving compliance. When adherence to recommendations is in the interests of individuals and public, and non-compliance is not a trivial matter, then the potential for improving compliance by modifying features of the health care service needs to be investigated.

Caplan (1979) suggests that a "diagnosis" of the health care service will indicate needed areas of change. An investigation into rates and reasons for attendance failure at clinics (Kellaway and Brown, 1980) listed misunderstandings, inconvenient appointment times, and excessive distance and cost of travel amongst reasons given. It is suggested that many of these can be relatively easily overcome by improved dialogue between clinic personnel and patients.

Sbabaro (1979) asserts that there is no justification for making people endure delays, inconveniences, and discourtesies. He suggests two possible approaches for ensuring sustained compliance, when adherence to a course of treatment is important. One possibility is for practitioners to administer or supervise the taking of drugs directly, and thereby minimise the need for patient co-operation, but questions are raised about the ethics of extending that kind of supervisory approach. The alternative is to provide the necessary support for the patient and his family over an extended period of time, even if the patient becomes unco-operative. Improved levels of compliance are consistently related to patient satisfaction with the practitioner and services provided (Matthews et al, 1977), and have been related to continuity of care (Hulka et al, 1976). The development of

health care services in which the patient is cared for as well as prescribed for emerges as a promising approach to promoting compliance. In this context, the positive attitude of the practitioner toward the efficacy of the regimen and his overt concern with compliance seems to have an effect on enhancing patient compliance (Marston, 1970).

COMPLIANCE IN RELATION TO CHANGES IN HEALTH CARE

In much of the research into patient compliance, there has been a concern to influence the behaviour by identifying predictive factors and to test interventions designed to enhance compliance. The thrust of research has been to investigate compliance with therapeutic regimens, and to a lesser extent, with proscriptive and lifestyle recommendations. An emphasis apparent in nursing research has been a concern with compliance with preventive and health promotion measures. Along with the growing preponderance of chronic sick as recipients of health care, there has been a shift in interest to that of compliance of patients with rehabilitative programmes and the management of prolonged treatment plans. In these contexts the contributions of nursing practice and research in assisting patients to comply with long-term health care plans are significant.

Compliance with Rehabilitative Programmes:

Articles reporting experiences in rehabilitating patients emphasise the importance of practitioners in motivating and assisting patients. The process of rehabilitation begins in the acute phase of illness, and Armitage (1980) uses the concept of "compliance" to refer to "good" and "bad" behaviour of hospitalised patients. She notes that expectations made of patients change along with the course of the patient career, and that patients are expected to become less dependent as recovery progresses. A study of compliance with self-care behaviour of patients who had had mutilating surgery was conducted in the early rehabilitative phase (Dropkin, 1979). It was found that those with a mature body image, and an

associated low need for approval of others, were more compliant than patients with a high need for social approval, even though noncompliance with self-care activities did not win approval from practitioners.

Hoepfel-Harris (1980) in describing a behavioural strategy to improve compliance with a cardiac rehabilitation programme, concludes that the success of the programme depends on the practitioners being able to motivate and assist patients to maintain changes in lifestyle over long periods of time. The development of specialised nursing services and the supportiveness of practitioners are basic to rehabilitative programmes in pain treatment (Kinnaird, Yohans, and Kieval, 1982) and stroke (Brady-Smith, 1982). Key variables in promoting continued compliance where there is no guarantee of recovery were to develop person-centred care, reduce barriers to compliance, provide honest and tangible guidelines, and to incorporate family and social support systems.

Patient Compliance with Long-term Treatment Plans:

The extent to which nurses have become involved in management of patients with chronic disorders such as hypertension is reflected in the number of programmes and investigation into patient compliance reported. Thomson and Willis (1982) report experiences in encouraging compliance of patients with a chronic respiratory condition with a treatment plan that included both prescriptive and restrictive recommendations. Multiple approaches were used to promote long-term patient co-operation. Foster and Kousch (1978, 1980) and Daniels and Kochar (1979) refer to the strategic positions that nurses occupy to facilitate the adherence of hypertensive patients with treatment plans, through the provision of quality and individualised patient care. An effective but simple strategy to improve compliance of hypertensive patients with clinic appointments was developed by Lowther and Carter (1981). Patients commented that they saw being sent reminder cards indicative of increased concern by clinic personnel, allowing them to feel important in a large health-care agency. The

effectiveness of the intervention can be attributed to greater patient satisfaction with care,

Along with the current trend toward psychotic patients being managed in community settings, the problem of noncompliance has become an issue amongst psychiatric nurses. Connelly (1979) and Hitchens (1977) suggest that patients can be assisted in continuing therapy through practitioners providing continuity of care and developing strategies such as tailoring in the context of a meaningful relationship with the patient. The importance of continuity of care and a positive therapeutic relationship is inferred from a study (Giberson et al, 1981) that found a significantly higher rate of compliance with follow-up psychotherapy amongst patients who had met their therapist prior to discharge.

O'Brien (1980) conducted a longitudinal study of 63 patients on haemodialysis, to determine whether the presence of strong support systems was associated with compliance of chronic patients over time. A positive relationship was found between both primary support groups - family and friends - and the secondary set - the dialysis centre staff - with compliance. Over time, the perceived support of both sets of support groups was consistently related to patient behaviour, but the expectations of care-givers were more strongly related to compliance than were those of the family. Implications are that the nurse-patient interaction in the clinical setting has significance for compliance.

Assisting patients with chronic disorders, such as those mentioned above, to comply with long-term treatment plans presents a particular challenge, in that exacerbations or further degeneration can occur in spite of patient co-operation. In this context the interaction between practitioner and patient for compliance assumes greater significance. Not only is it necessary to motivate and maintain patient compliance with the regimen over prolonged periods of time, but there is a need to support the patient

and his family to cope with changes in lifestyle and crises that occur,

Patient Compliance as an Outcome of the Practitioner-Patient Interaction:

There are indications in literature that the practitioner-patient interaction has been demonstrated to be amongst few variables predictive of compliance, and yet undue emphasis has continued to be placed on one interactant, the patient, with few empirical investigations into the interaction (Svarstad, 1976).

Davis (1968) recorded and analysed (with Bale's categories) 223 interviews, and related findings to a composite compliance index. Of the subjects, 37 percent were non-compliant, and while no relationship with demographic variables could be demonstrated, there was an association with the patient-physician relationship. Poor compliance was related to deviant communication patterns such as when tension remained unreleased, whereas contractual arrangement emerged as being most positively related to compliance. In a study by Svarstad (1976) an interactional framework was employed by which the total effort made by the practitioner to motivate the patient was measured. This effort was found to be positively related both to the level of instruction the patient received, and to compliance as an outcome. In both studies, improved patient compliance was conceptualised as an outcome of the interaction, and patient satisfaction and good communication emerged as significant factors.

Stone (1979) suggests that when compliance is seen unilaterally as patient behaviour, the practitioner can react by denying the occurrence or extent of noncompliance, or consider it as outside the scope of his responsibility. He may also take on himself full responsibility for ensuring compliance, and experience considerable frustration at his limitations in motivating patients. From an interactionist perspective, Stone proposes three complementary aspects to

professional responsibility. He emphasised that the patient's ability and motivation to comply should be explored by the practitioner, and that the latter should have a background of knowledge of the dynamics of human behaviour and of communication theories, as well as developed skills in these areas.

A small number of studies have specifically investigated the effect of nurse-patient interactional strategies on patient compliance. Two studies, one involving the very young and the other the elderly, were conducted against a background of increasing demand for ambulatory medical services. Nurses were used in a supportive and counselling role, while physicians were concerned more with diagnostic and therapeutic activities. In both studies, the effectiveness of the nurse interaction was attributed not to differential abilities of practitioners, but to differential processes of care. Lewis and Resnick (1967) found that the experimental group of elderly patients, who were supervised by nurses instead of physicians, had less days as inpatients, and half the rate of broken appointments compared with the group supervised by physicians. Furthermore, nurses tended to spend more time with patients.

In the other study referred to, nursing and medical supervision were not compared, but nursing services were added to normal paediatric services, in the form of "Family Health Management Specialists" (Fink, Malloy, Cohen, Greycloud, and Martin, 1969). The nurse consulted with the child's family while waiting to be seen by the physician, and compliance rates of the experimental group were much more favourable than that of the control group. It was concluded that the significant factor in improving compliance was the time spent with clients, rather than the nature of the intervention. A similar study was conducted recently (Thibaudeau and Reidy, 1977) in which compliance was selected as an outcome measure of an intervention using a dynamic nurse-patient interaction. While physicians treated the child's illness, nurses cared for mothers under the stress of having a sick child. Findings were that the rate of compliance in the experimental group who received the

intervention was significantly higher than that of the control group.

Potential of Nursing Practice to Promote Patient Compliance:

The point that nurses are in a strategic position to assess, monitor, and enhance patient compliance to health care plans is evident from the number of reports of experiences in practice settings as well as experimental intervention in which nurses take a major role. Roy and Obloy (1978) suggest that there is potential within the scope of nursing practice situations to observe factors that are related to compliance, and then to test constructs developed from empirical observation, thereby contributing to knowledge of compliance. Moreover, the nature of nursing practice and the associated view of the patient primarily as a person, in contrast to being a host for disease, suggests that contributions of nursing to further understanding about compliance will be unique (Weintraub, 1975). Hogue (1979) and Steckel (1982) suggest that the particular approach in practice to improve compliance should be related to the nursing perspective on the patient.

That perspective, it is argued, is in contrast to the disease-oriented approach of medicine, and views the patient as a whole person, focussing on wellness and health as well as disease. A person-centred approach consistent with that perspective takes account of values and lifestyle, and utilises knowledge the patient may have of his own body (Paulen, 1981).

Hogue (1979) draws attention to the long interest of nursing in the problem of noncompliance, and the particular involvement of nursing in assisting patients with chronic sickness in complying with long-term health care plans, be they preventive, rehabilitative, or therapeutic. There are indications that there is a positive relationship between increased participation of the patient in the therapeutic process, and compliance. The development of a nurse-patient

relationship in which patient participation is encouraged is consistent with the concept of "therapeutic alliance" (Moughton, 1982). In this context, it is recommended that the supportiveness of the nurse and a mutually participative interaction between nurse and patient receive attention in both practice and research (Hogue, 1979). Nursing action to encourage compliance as an outcome of a participative nurse-patient relationship needs to take account of the patient's point of view.

THE PERSPECTIVE OF THE PATIENT ON COMPLIANCE

There is a paucity of literature discussing compliance from the point of view of the patient, and no research reports with that focus have been located. Stimson (1974) has attributed this neglect to the conventional view of the practitioner as the expert in health matters, with the blame for compliance failure lying with the patient.

In a sympathetic discussion of patients' management of regimens for chronic disease, Strauss (1975) focuses on the demands and effects, both physiological and social, that the regimen may make. Compliance may fluctuate as a result of the difference the regimen is making to the person's well-being and lifestyle in the here and now. Therefore, practitioners need to offer help, support, and reinforcement appropriate to these fluctuations and on an on-going basis, in order that acceptable levels of treatment will be maintained.

Maintaining compliance in the absence of symptoms is a particular problem. Mechanic (1972) suggests that to stop taking medication and attending clinics when one feels better is logical and commonsense, especially if such requirements are costly. Commonsense explanations for behaviour can only be obtained by asking the patient. The explanation for noncompliance with medication can be as straightforward as when an arthritic person is unable to open childproof containers, or a partially paralysed person unable to swallow large pills (Potter, 1981). To examine compliance behaviour as it appears from the outside can give rise to complex and abstract explanations, with the patient's position being overlooked or ignored.

In a pilot study in which a small convenience sample was used (Roberts, 1982) the relative importance of patient problems as identified by patients and their nurses were compared. Patient compliance was one of the 21 problems considered, and was ranked lowest in order of importance by patients, and thirteenth by nurses. It is inferred that it is necessary to ascertain the importance of compliance as perceived by patients, and the level of agreement between patients and practitioners, in order to promote compliance through a participative therapeutic relationship.

It is relevant to note here that in a study aimed at identifying the characteristics of women who were potential users of preventive health services Triplett (1970), in common with many other studies, found that no relationship could be established between degree of usage and characteristics identifiable from the "outside", such as education, age, and social class. However, a direct and significant relationship was found between the degree of disparity that was perceived by subjects between themselves, and health care workers, with an associated threat in interacting.

One article described the experiences of recipients of health care suggesting that different perspectives of patients and practitioners on compliance can negatively affect the interaction and constitute a problem for patients (Hoover, 1980). Being labelled as "noncompliant" puts an added burden of frustration, guilt, and stigma on someone already trying to cope with a disease. A noncompliant patient is perhaps unconvinced of the value of the regimen, which suggests the need for sharing of information and negotiation between practitioner and patient. The aim is to have the patient not simply acquiescing, but rather following recommendations because he has made a choice to do so.

A more active view of the patient is indicated - one that sees him as rational and active both in decision-making and in managing the regimen along with daily living. Some, e.g. Brody (1980) would hold that to do less is to treat the patient as a nonperson and to negate his capacity for autonomous, responsible behaviour. In somewhat similar vein, Stimson (1974) argues that patient compliance is a social problem, the nature of which is understandable only in terms

of the patient's perspective on his situation, and the solution for which lies with using human rather than technical interventions. The pattern of patient behaviour in terms of co-operation with recommendations and adherence to health care plans becomes understandable when the point of view of the patient is taken, and his perceptions on health, and on his illness and treatment, are interpreted.

SUMMARY AND CONCLUSIONS

To an increasing extent, the active participation of patients in their own health care and therapeutic regimens is being required. The phenomenon of patient compliance is an important factor to the effectiveness of health care services, and noncompliance is identified as one of the most serious obstacles in the control of communicable diseases in man.

As the magnitude of compliance failure became evident, research efforts have been directed at identifying factors that could be used to predict compliance. The inconsistency of findings is attributed to the use of a medical model to explain a social phenomenon. Socio-behavioural models have demonstrated greater powers of explanation, but factors identified are relatively immutable, and therefore not appropriate targets for intervention. Recently, attention has turned from explaining noncompliance to developing and testing strategies designed to improve compliance.

A universal finding that compliance returns to baseline levels once interventions are terminated, together with indications that compliance is positively associated with patient satisfaction and continuity of care, suggest that changes in the way health care services are provided have greater potential for improving patient compliance in the long term. This finding highlights the importance of the therapeutic relationship, particularly in the care of chronically sick patients. The encouragement of full participation by the patient and his family in the health care process, is seen as a desirable way of encouraging patient compliance in the context of

person-centred, holistic care.

There is a need to develop the relationship from the patients' point of view, based on data that is empirically validated, rather than on assumptions. For these purposes, it is appropriate to use patients and others close to them as sources of information and explanation, so that the meaning that compliance has for patients can be better understood.

CHAPTER FOUR

STUDY DESIGN AND METHODOLOGY

The choice of design and method of study were influenced by the purpose of the study. As stated earlier, the purpose of the study was to make compliance more understandable by interpreting compliance from the patients' point of view. It was argued that data obtained in the natural context would have greater validity for this purpose.

The chapter begins with a discussion of the interpretive research approach. The aim of the study and the study design are specified. Terms used are defined, and ethical considerations briefly discussed. A full description of the data collection is then presented. The chapter concludes with an outline of the manner in which data analysis was approached.

THE INTERPRETIVE APPROACH

The interpretive approach is a research strategy that is considered particularly suitable for the study of clinical nursing phenomena under the conditions in which they naturally occur. The approach requires the researcher to attend to the perceptions and explanations of the subjects of the study (Anderson, 1981; Stern, 1980).

Two standard paradigms of research in the social sciences are the normative paradigm, and the interpretive paradigm (Bullivant, 1978). The normative paradigm, so called because of the emphasis placed on norms of explanation, has adopted the hypothetico-deductive "scientific method" of the natural sciences. Hypotheses derived from extant theory are verified, and value is placed on objectivity, asserting that the greater the distance the researcher is from the subject, the more valid and reliable the data. A questioning of the validity of the objective stance and its a priori assumptions that the method of natural sciences is equally applicable for behavioural sciences, has led to a search for alternative models of inquiry within the social sciences (Filstead, 1970). The normative paradigm has been criticised also for having elevated method over theory, and of having largely overlooked or

ignored the implications of subject matter for deciding the method of research (Bullivant, 1978).

Referring specifically to the study of compliance, Feinstein (1976) notes the deficiencies of quantitative data in explaining what is essentially a subjective phenomenon, and that qualitative data obtained directly from the patient increases the probability of interpreting compliance accurately.

The interpretive paradigm has its origins in ethnographic methodology, which utilises the technique of participant-observation. The aim is for the researcher to get close to the data in order to interpret the social world from the actor's inner, subjective perspective. According to the normative paradigm, people act out prescribed roles in society, which can then be described objectively by the researcher. In contrast to this, the interpretive approach holds that people actively make roles according to the way social reality is interpreted. From a phenomenological and social interactionist perspective, it is the researcher's task to interpret, or uncover, the way participants apply meanings and rules in social life in the context in which behaviour takes place naturally (Bullivant, 1978).

There is a corresponding shift of emphasis from verification of theory, within the normative paradigm, to generation of theory, by the interpretive approach. Glaser and Strauss (1967) argue that the identification of concepts and hypotheses within the phenomenon being investigated and the generation of theory out of empirical data would produce a closer fit of theory with social reality. The approach welds together theory, method, and technique, in contrast to an artificial separation of theory and method that results from the primacy placed on method within the normative paradigm (Bullivant, 1978).

The common criticisms raised against the interpretive approach are that it lacks rigor, justifies sloppiness and arbitrariness of design, and unjustifiably assumes freedom from prejudice and presuppositions (Blumer, 1979; Cohen, 1980). Blumer questions whether, in fact, concepts and theory emerge out of the substantive

area, and suggests that an interplay between data and conceptualisation more correctly describes the process. He further suggests that grounded theory is weak in providing justification and validation for concepts that are identified. However, when the overriding issue is one of explaining a substantive area of social reality, rather than one of precision of measurement, the qualitative approach is appropriate (Bryn, 1970). It is further argued that theory generated from the systematic collection and analysis of data allows for creativity and insight on the part of the investigator. That process is discouraged by the value on objectivity within the hypothetico-deductive model, but is a valued factor in developing theory intended to explain social reality (Glaser and Strauss, 1970).

Strategies that are consistent within the interpretive paradigm aim to bring a situation or behaviour from unintelligibility to understanding, and emphasise that understanding can only take place in the context of the system in which it is embedded (Watson-Franke and Watson, 1975). The basic strategy of the interpretive paradigm is dialectical questioning. This process is substantially different from, but not necessarily less rigorous than, the verification of hypotheses within the normative paradigm (Bullivant, 1978; Watson-Franke et al, 1975). Dialectical questioning contrasts with the linear process of methodically answering prestructured questions. The process characteristic of dialectical questioning is an ongoing interaction between questioner and informants, with the interviewer drawing out further detail, clarification, different perspectives, and shades of meanings. By going to and fro, the answer to the question represents a drawing together of multiple answers, facets of the one phenomenon, and thereby the meaning of the situation is made more understandable to the outsider. The essential difference between methodical and dialectical questioning is that in the former (the kind used in survey techniques, prestructured interviews, and questionnaires), the answer is potentially present in the question, while dialectical questioning breaks the barriers of prejudgement of significant concepts. Through the process of dialectical questioning, it may become apparent that the question itself needs to be discarded as inappropriate or irrelevant (Watson-Franke et al, 1975).

An interpretive research design utilising the strategy of

in-depth interviewing in the field setting was selected as an appropriate method of inquiry into patient compliance.

THE RESEARCH QUESTIONS

The aim of the study was to contribute to the understanding of compliance behaviour by generating answers to the following question;

What does compliance mean to persons with tuberculosis who are obligated to adhere to a protracted therapeutic regimen, and other related recommendations?

Questions arose in relation to the central question:

What are the subjective experiences of patients in complying with treatment plans in the domestic setting, and in relation to the illness experience and lifestyle issues?

What are patients' perceptions of the ways in which practitioners prepare, assist, and motivate patients in complying with treatment plans?

RESEARCH DESIGN

An interpretive research design was selected in order to obtain first-hand knowledge about patients' perceptions and subjective experiences of compliance.

An interpretive design is a research strategy based on techniques such as participant observation, in-depth interviewing, and interacting in the phenomenon being investigated. By the process of dialectical questioning, knowledge is discovered and verified concurrently. Concepts are identified, and qualitative data about their properties and relationships documented, in the setting in which they naturally occur. In this way, the phenomenological aspects of the substantive area being studied can be interpreted. That is to say, the inner perspective and

subjective definitions of behaviour provide the core of knowledge. This requires that the distance between researcher and informants is minimised, and that the researcher is close to the data (Filstead, 1970; Bullivant, 1978; Anderson, 1982).

Field Research Method:

Distance between the researcher and the area of investigation in the present study was minimised by the use of the field research method. While participant observation is the technique commonly employed in interpretive research, certain features of the regimen to which patient compliance was being studied precluded its use for observing much of the relevant data. For instance, medications are taken first thing in the morning and intrusion into the domestic setting to that extent was considered to be unwarranted. Therefore, in-depth interviews were conducted with patients and members of their households in their domestic environments, and by this means, their perspectives on compliance were uncovered. The interviews were not structured, but took the form of guided or focused conversations, in order to ensure that particular themes, as specified below, were covered. Themes intended to be explored were:

- 1) The illness itself, and the effect it had on patients.
- 2) The prescribed regimen, its duration and effects.
- 3) Lifestyle adjustments, and the effects both the illness and the prescribed regimen have on the way of life of patients.
- 4) Barriers to compliance, that constitute difficulties to patients in adhering to prescribed regimens.
- 5) Facilitators to compliance, covering factors and personnel that have assisted and supported patients in adhering to the regimen.

In-depth, qualitative data covering these themes were generated through the process of dialectical questioning, by which problems were thrown up, and dialogue triggered. In this way, it was possible to explore several factors simultaneously,

as patients' perspectives on compliance in relation to other aspects of the illness experience were interpreted. Pretesting of method of data collection is not indicated in interpretive research, but rather, on-going evaluation not only of the method of obtaining and verifying data, but even of the research questions themselves, accompanies the research process. In this way, empirical data and theory generated out of it are intimately linked, so that theory is relevant and usable because of the fit maintained (Glaser et al, 1967; Watson-Franke et al, 1975). At the same time, the generation of rich, in-depth data requires neither a large nor randomly-selected sample. However, generality of the theory developed from findings is likely to be enhanced when the study population reflects the same kind of variability as is likely to be found in a wider population. The selection of participants (see p. 67) was influenced by this consideration.

Because qualitative data are not readily collected in a concise form, accuracy was ensured by recording dialogue on tape. Concepts were identified in data through an initial analysis. These were then further investigated and verified in the on-going research process. It was intended to enhance the quality of data by including, where possible, other household members in the interviewing, and to verify information obtained with members of patients' families, and with practitioners.

Objective Measurements of Compliance:

In order to supplement qualitative data on compliance, it was intended to use a five-point Likert-type scale, by which patients would rate their compliance behaviour, making a distinction between whether noncompliance was intentional or by error. An example of the scale is presented below in Fig 2:

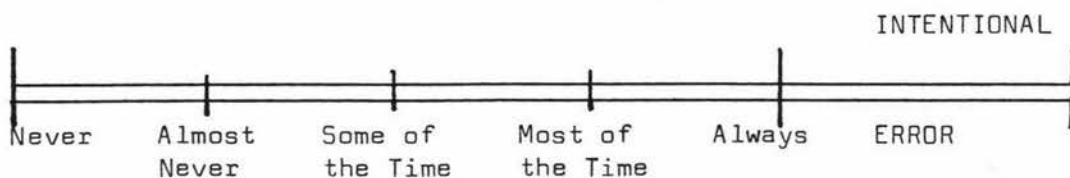


Fig 2: Scale for Self-Rating of Compliance Behaviour

It was hoped that discussion on perceptions and experiences of complying would be initiated by asking the person to rate the extent of his compliance with the treatment plan. At the same time, the use of a scale to self-rate compliance would provide an objective measure.

Noting that the use of multiple measures of compliance provides more complete data and minimises error associated with a single index (Dunbar, 1979), consideration was given to ways in which participants' reports could be verified objectively. Methods that relied on the manipulation of factors or were intrusive were rejected as inappropriate to a study of compliance in the natural setting. The use of pill counts to cross-check self-report was considered, as the method has been used successfully in the domestic setting in other studies (Roth, 1979). As the research proceeded, it became evident for reasons which will be explained in a later section that to do so was not feasible in this study.

DEFINITION OF TERMS

Compliance is defined broadly as the extent to which the patient's behaviour coincides with the prescribed therapeutic regimen, and other related recommendations.

More specifically in this study, three aspects of compliance were of particular relevance:

- 1) Compliance with taking prescribed medication: the extent to which the taking of medication coincides with prescribed type, dose and frequency of medication.
- 2) Compliance with clinic attendance: presentation at the outpatient clinic for follow-up and renewal of medication prescriptions on the appointed date. Compliance with referrals to other consultants or departments, or for diagnostic or therapeutic procedures, were included as related behaviours.
- 3) Compliance with other recommendations: these covered
 - a) the extent to which action taken to minimise the risk of

- transmission (e.g. in relation to protection of others from droplet spread) coincides with recommendations.
- b) the extent to which recommended health promotion activities were followed.

CRITERIA FOR SELECTION OF PARTICIPANTS

Criteria for inclusion were:

- 1) Medical Diagnosis: a confirmed diagnosis of tuberculosis, which was currently being treated on an ambulatory basis.
- 2) Age: adults between 16 and 70 years of age.
- 3) Mental Status: no intellectual handicap, or recent history of psychiatric illness.
- 4) Language Fluency: sufficient command of English to be able to conduct a conversation with the researcher, or, in the absence of this, another member of the family willing, able, and available to act as interpreter.
- 5) Informed Consent: written agreement to participate in the study after requirements and implications had been fully explained.

ETHICAL CONSIDERATIONS

The nature of the study was explained to patients who met the criteria for inclusion. Information was given about the identity of the researcher, the purpose of the study, and the requirements of participants. The following assurances were given to potential participants:

- 1) Participants were informed that they were free to withdraw their consent at any time.
- 2) The wishes of participants regarding the use of the tape-recorder, and inclusion of other household members in the interview were respected.
- 3) Confidentiality and anonymity of participants were preserved.

- 4) Assurances were made to patients and practitioners that there would be no interference with the policy of treating ambulatory patients, the regimen would not be manipulated, and the work of health care practitioners would not be interrupted.

Written consent was obtained from patients who indicated their willingness to participate in the study.

DESCRIPTION OF THE SETTING FOR THE STUDY

The study was conducted in a large metropolitan area. The locale was selected for two reasons:

- 1) Health Department statistics indicated that a large number of tuberculosis patients, potentially suitable for inclusion in the study, were resident in the area.
- 2) The effect of certain extraneous variables such as multiple institutions and policies of management were eliminated. All adult tuberculosis patients are initially hospitalised in one ward of a particular hospital, and their follow-through as outpatients takes place in the chest clinic of that same hospital.

The interviews and observations were conducted in the patients' homes. On two occasions, participant-researcher interactions took place in the waiting room of the chest clinic. The researcher consulted health services personnel in their workplaces.

DESCRIPTION OF DATA COLLECTION

The study was conducted over a twelve week period, from December 1982 to February 1983 inclusive, during which time patients taking antituberculosis medication on an ambulatory basis were visited in their homes, and in-depth interviews conducted. A total of 98 house calls were made over the metropolitan region in which the study was conducted, which yielded 78 visits, ranging between two and seven

visits per participant, at which time qualitative data were collected. In addition, patients taking medication who were not yet discharged from hospital were questioned, and practitioners attached to the health care agencies which provided services to patients were consulted.

Description of Patients Included in the Study:

Twenty-two patients who met the criteria for selection and consented to participate were included. Selection of participants proceeded in the following manner.

Application for access to names of registered Tb patients was made first to the Health Department in the district selected as the locale for the study. Because the names of patients currently taking medication were not readily accessible, the application was referred to the hospital where Tb patients are treated. The senior chest physician was agreeable that the researcher could have access to medical records of tuberculosis patients, and to the patients: this permission was ratified by the Medical Superintendent's office.

From a search of the ward admission book, the names of patients between the ages of 16 and 70 years of age who had been admitted during the previous twelve months were noted. From that list, names were deleted if the medical records were not locatable, or if the medical records indicated that certain criteria were not met. A decision was made not to include refugees from south-east Asia, in view of the probability of communication difficulties, and in consideration of the stress associated with a refugee status and with recent immigration.

Thirteen patients who met the first three criteria were later excluded because of

- Present address unknown or now outside the region in which the study was being conducted.
- Language difficulties (one was aphasic).
- Refusal to participate (one only).
- Not at home when researcher called (initially or on following occasions), and no response to written messages left at house.

In all, 22 patients met the criteria and agreed to participate. These constituted the study group, whose characteristics are described below.

Characteristics of Participants: Data obtained from medical records showed patients to vary in relation to age, ethnicity, socioeconomic status, and clinical manifestation of the disease. Demographic characteristics of participants are presented in Table 1. An index developed by Elley and Irving (1982) based on male occupation categories, was used to categorise socioeconomic levels.

Table 1: Demographic Characteristics of Participants of the Study

Character- istics	SEX		AGE (in years)			ETHNICITY				SOCIOECONOMIC STATUS	
	Male	Female	16-29	30-55	56-70	Caucasian	Maori	Pacific Islander	Asian	Higher Levels (1 - 3)	Lower Levels (4 - 6)
Numbers	12	10	3	13	6	7	5	8	2	5	17
TOTALS	22		22			22				22	

Clinical Manifestations: There was variation in the site and severity of the disease, as well as to the duration of time since commencement of treatment.

Seven people had been taking treatment for less than three weeks, ten for between three and nine months, and five for over nine months.

Nineteen had pulmonary tuberculosis, with Tb meningitis, renal Tb, and Tb adenitis and of wrists each accounting for one instance.

Five of the participants had had a previous episode of tuberculosis. In five of the households, another person in addition to the participant also had Tb. Of these, three had had the disease recently, prior to the participant contracting it, and two were discovered during contact tracing procedures.

The response to treatment was uncomplicated for twelve patients, while six others responded only slowly to treatment. Another two patients experienced drug reactions sufficiently severe for treatment to be withdrawn. Three patients were found to have an organism that was resistant to at least one of the commonly used drugs. Two of these were required to be treated surgically and with reserve drugs.

As the researcher has no means of comparing the clinical characteristics of the study group with other populations of Tb patients, it is not possible to state that these kinds of manifestations are representative of any sample of Tb patients. The range of characteristics in respect to age, sex, ethnicity, and socioeconomic background, however, reflects that found in a wider population of Tb patients.

Description of Other Informants:

Additional information was obtained and data verified through consulting the following:

Family Members: Other household members were invited to participate in interviews provided the patient was agreeable. Family members of twelve patients participated.

Hospitalised Patients: Two patients commenced on anti-tuberculosis therapy but not yet discharged from hospital were questioned to verify certain data.

Health Services Personnel: For the purposes of obtaining background information on tuberculosis management in that

agency, and to verify patients' statements, the following personnel were consulted,

- senior nursing personnel in the Tb ward, Chest Clinic, and Health Department, and three practising public health nurses,
- chest physicians, one at the hospital, and one at the Health Department. In addition, one general practitioner, and the pharmacist at the hospital who was responsible for dispensing the antituberculosis medication for inpatients,
- social workers, attached to the hospital, and to voluntary agencies,

Procedure:

After suitable patients were selected, the study proceeded as follows.

Introductory Visit: The first visit was not prearranged, and constituted the initial contact between researcher and patients. The purpose of the visit, nature of the study, and the requirement of participants were explained. Patients were informed that a study was being undertaken by a nurse-researcher, which was concerned with how Tb patients coped with continuing with prescribed treatment after discharge, and with the necessary adjustments brought about by the illness experience and associated treatment. They were then told that those who were willing to participate would be visited further on two or more occasions, when interviews would be conducted. It was stated that preferably the next interview would be tape-recorded, and suggested that other family members could also participate.

After establishing the patient's willingness to participate, written consent was obtained. Arrangements were then made for a subsequent visit.

Information and observations were recorded in fieldnote form as soon as possible after the visit.

Main Visit: The interaction began informally with a sharing of general information, providing the participant with opportunity to voice concerns he may have about the study, and to ask the researcher any questions he may have. It was made clear, as similarly encouraged by Blum (1970), that at any time during the interview the participant was free to reciprocate questioning, and was not obligated to discuss any issue he may object to.

When the interviewer was satisfied that any reservations the participant may have had were dealt with, and that rapport was established, conversation was guided toward the themes to be covered in the interview. At this point, tape-recording of the dialogue commenced, with the exception of two instances, where the participants requested otherwise. While the themes were not covered in any particular order, the dialogue frequently began with the patients describing their illness experience. Through attending to patients' expressions of their perceptions of the disease and the impact of the illness on their lives, the conversation could be focused in a non-threatening manner on compliance with the treatment plan. In accordance with guidelines laid down by Filstead (1970) the flow of information from the inner, subjective perspective on compliance and related themes was encouraged by sympathetically listening to the patients' accounts. When the themes had been covered, the interview was drawn to a close, and arrangements made for the next visit.

Observations and information that was not tape-recorded were documented in fieldnote form as soon as possible after the interview. Tapes were transcribed soon after the interview took place, and before the next visit. The transcriptions were subjected to an initial analysis, and notations made of information to be cross-checked or themes to be further explored.

Subsequent Visits: A follow-up visit took place within a week of the main visit, at which time further information

was elicited, statements clarified, patients provided with feedback, and certain inferences or conclusions drawn from preceding interviews shared to ensure that the patients' perspectives had been correctly interpreted. This interview was not tape-recorded, but fieldnotes were made of the dialogue.

When the researcher was satisfied that the themes had been thoroughly covered and that there was nothing to be gained from further discussion (a process described by Glaser et al (1967) as saturation of themes), the relationship was terminated. This usually occurred after the third visit, but further visits were necessary for six participants, where either data had not been forthcoming, because of poor rapport or interruptions, or where further verification was required.

Excerpts from each phase of the interaction are given in Appendix 1 (a), to show the process that occurred.

Objective Methods of Measurement Abandoned: As the study proceeded, it became evident that certain objective measures intended to supplement qualitative data were unhelpful in furthering understanding of compliance from the patient's point of view.

The Likert-type scale by which patients were to self-rate their compliance behaviour was introduced. It became apparent early in the study that patients had difficulty in deciding where their behaviour fitted on the scale, although the same difficulties were not evident when they described their compliance in the course of interviewing. Further, the introduction of the scale had an inhibitory effect on conversation, thereby interfering with the generation of qualitative data. The use of the scale to rate compliance was discarded after the third interaction.

The use of pill counts to cross-check patients' reports of compliance was not feasible in the present study. In order to measure compliance by comparing the number of tablets on hand at any point in the course of treatment with the number initially supplied to the patient, it is necessary for there to be a precise record of the latter information. Such information was not available to the researcher, largely because the prescriptions were filled by multiple private pharmacies, rather than from the single source of the hospital pharmacy.

An advantage of the research design, as suggested by Watson-Franke et al (1975) is that if it becomes apparent that foci and means of gathering data are inappropriate or irrelevant, they can be discarded. Questions and methods that prove helpful in meeting the aims of the study are retained and developed (cf. Glaser et al, 1967).

Methodology of Data Collection:

In order to meet the principal aim of the study, namely to interpret compliance as experienced by the patient rather than document the behaviour as it appears from the outside, in-depth interviewing in a field setting was utilised, as is advocated by Anderson (1981). The interviewing technique allowed data to be gathered, recorded, analysed, and verified in a recurring sequence, in accord with the process described by Becker (1970). The interviewer was the principal instrument in this process.

Position of the Researcher: Quint (1967) has noted that the disadvantage of nurses investigating patient care phenomena is that familiarity with situations can produce a blind spot. However, in this instance the researcher had not been involved in the supervision of Tb patients in New Zealand, and was not in the employ of the particular agencies whose patients were participating in the study. In fact, it was possible to take advantage of the statuses both of nurse and researcher. The researcher's identity

as a nurse was known from the outset, and it was her impression that patients responded positively to requests for their participation because of familiarity with the existing relationship between nurses and patients as categories of people (cf. Rubin et al, 1976). This relationship, together with the researcher's familiarity with the health care system, facilitated the establishment of rapport and trust. On the other hand, their perception of the interviewer as researcher seemed to encourage some subjects to relate their experiences, opinions, and expectations very frankly.

Use of the interpretive paradigm requires the researcher to get as close as possible to the data, so that the subjective experiences of participants can be uncovered. However, Vidich (1970) suggests that the researcher needs to maintain the outsider status and some social distance, in order to be able to interpret that experience to outsiders. It is recognised also that the data are affected by the status participants ascribe to the researcher, and that this is likely to vary between participants and over time. In the present study, the statuses as nurse and researcher were given different emphases by patients included in the study. The researcher needed to make a deliberate, conscious effort to maintain a status that was seen as independent of the health care agencies.

Generation and Verification of Data: The phenomenological orientation, with its focus on uncovering the inner, subjective view of compliance, required that persons involved were given scope to explain their experience in depth. The following themes were explored in these guided conversations.

- Patients' self-reported compliance behaviour,
- The prescribed regimen, including perceived complexity and duration,
- Facilitators and barriers to compliance that were

perceived or experienced in the domestic context,

- The inpatient experience as preparation for compliance after discharge,
- The perceived importance of compliance, other health issues, and the illness experience, relative to personal and social issues,
- The experience of being ill, and specifically of having tuberculosis,
- Other issues that were raised by the patients in the interviews were noted as significant in the patient's subjective experience.

Through covering these themes, data were generated about compliance with the following specific kinds of recommendation,

- 1) Compliance with the Medication Regimen: To rely on self-reports of compliance behaviour was considered to be consistent within the design of the study. These data were cross-checked and verified when appropriate with other members of the household, and with practitioners. Confidence in patient self-report, often regarded as an unreliable measure of compliance, was enhanced by attention to detail and consistency of the patient's report. If participants were able to describe the tablets, dosages, and schedule of the regimen, it was inferred that their familiarity was because of high rates of compliance. Inferences were further verified when participants specified instances of omission. At each visit patients were asked if they had taken medication that day, and affirmative responses on at least three days over a two week period further verified self-reported compliance.
- 2) Compliance with Appointment at Clinic: This was assessed objectively by referring to medical records held at the clinic, and subjectively from explanations offered by participants.
- 3) Compliance with Other Recommendations: Participants' self-reports were verified by observations made by the

researcher (e.g. of cigarette smoking, protection of mouth when coughing), and by comments made by other household members in some instances.

Examples of checks on the internal consistency of interview data are given in Appendix 1 (b).

Freedom from a schedule that had to be rigidly followed through allowed the researcher to pursue lines of inquiry as the significance of these emerged from the data. Thereby a close fit between the subjective experience of compliance and the data could be maintained throughout the process of generation and verification of data.

DATA ANALYSIS

As indicated earlier, and consistent with the research design, data collection and analysis proceeded in recurring sequence, along the lines recommended by Becker (1970). Pieces of information and indicators that emerged during an initial analysis of transcribed interviews were noted, and verified or explored further in subsequent interviews. An example of the way this was carried out is given in Appendix 1 (c).

While noting that provisional field analysis gives direction for further generation of data, Becker draws attention to limitations provided by field conditions. A final comprehensive analysis is therefore indicated after data collection is completed. In the process of systematically rechecking concepts identified provisionally, an explanatory model to explain the phenomenon is constructed. Noting that there is no clear separation between phases of problem identification, data collection, and analysis, Pearsall (1970) describes the goal of each phase as being to maximise knowledge and understanding of the behaviour by incorporating research findings into theory. It may be appropriate to modify extant theory to fit the substantive area as interpreted phenomenologically, or to construct a new model out of data, a choice which will become clearer as data are analysed,

The present study followed a similar process to that described by Pearsall (1970). Certain problems and indicators that were seen as potentially relevant themes to investigate in this study were identified in a review of literature, and are presented in the discussion of the research design (p.61). These were subdivided and refined as a result of initial analysis of data concurrent with its collection, and the modified list of themes is presented in the description of methodology of data collection (p.73).

The concept of patient career (as discussed in Chapter two, p.17) was employed as a framework for conducting the study, and as a final comprehensive analysis of data proceeded, the potential of the model, in modified form, to explain compliance behaviour, became evident.

Becker (1970) discusses the difficulties that arise in presenting qualitative data. They do not lend themselves to a succinct and economical presentation of findings, and yet it is in the presentation of data that evidence for conclusions is provided. Findings and inferences will be presented in full in the following chapters, and examples will be included to provide evidence for conclusions.

SUMMARY

An interpretive research design was selected as appropriate for inquiry into compliance from the subjective point of view of the patient. Qualitative data were generated through the strategy of in-depth interviewing in the field setting. Concepts were identified in empirical data through an initial analysis of data, and findings were cross-checked and verified by the ongoing process of dialectical questioning, both with patients, and with other persons associated with the patient where appropriate. An additional provision made for collecting quantitative data to supplement the qualitative perspective were shown to be inappropriate in the context of the present study.

The interviews were conducted in the homes of the 22 participants, with other family members of twelve patients also participating. Health

care personnel were consulted to further verify certain data, and to provide background information. Time was also spent observing in the ward and clinic, at which time two inpatients were questioned to verify certain information.

Findings are presented and discussed in Part Two of this report.

CHAPTER FIVE

COMPLIANCE - EXPECTATIONS AND RESPONSES

Compliance has been defined broadly in Chapter Four (p.63) as the extent to which patients' behaviour coincides with the prescribed therapeutic regimen and other related recommendations. Regimens and other measures that are generally employed in the management of tuberculosis have been discussed in Chapter Two. The present chapter begins with a description of policy and standard practices in the treatment of tuberculosis by the agency whose patients participated in this study. However, to measure compliance behaviour of patients objectively against standard practice without specifying precisely what prescriptions and recommendations were made to those patients, could yield misleading results. Participants' interpretations of their treatment plan and expected behaviour are discussed as compared with standard recommended practice. Finally, from the self-reported experiences of participants, it is seen that patient compliance is not a uniform response to medical orders. The explanations of participants about adherence to prescribed regimens as compared with proscriptive recommendations are presented.

PRESCRIPTIONS AND RECOMMENDATIONS

The two agencies that have been involved to a greater or lesser extent in the treatment of tuberculosis patients and control of the disease as outlined in Chapter Two (p.10) are public hospitals and the Health Department. In the district in which the study was conducted, the public health nursing service was until recently responsible for domiciliary supervision of patients after discharge from hospital. Because of changing priorities of the nursing service as a response to shifts in disease patterns in society, the policy regarding supervision of ambulatory Tb patients is in the process of being negotiated.

Currently in that district, patients receive inpatient and out-patient care at the hospital, where all investigations take place, antituberculosis therapy is prescribed, and follow-through surveillance is provided. The Health Department is involved in the following up of suspected Tb patients, tracing of contacts, mass screening and immunisation in certain areas, and in contacting patients who have defaulted clinic appointments. Public health nurses continue to supervise selected patients in their homes, a matter which will be examined in greater depth in Chapter Seven.

Thus it is the hospital that is seen to be the health agency concerned to the greater extent with the treatment and supervision of Tb patients.

Purpose of Hospitalisation:

From statements made by practitioners and participants, the period of hospitalisation emerges as being an important period in preparing patients for compliance with treatment in the domestic environment.

The stated purposes of hospitalisation, as emerged from consultation with practitioners and printed guidelines, are:

- 1) to confirm the diagnosis of tuberculosis,
- 2) to establish antituberculosis therapy, and at the same time -
 - (a) to monitor patient tolerance to the chemotherapeutic regimen, particularly observing for drug reactions,
 - (b) to prepare the patient for continuing this regimen at home, after discharge, by a system of "Individualised Patient Medication"¹ by which patients are responsible for self-administration

¹ By the system of "Individualised Patient Medication" each patient is supplied with his own medication and is responsible for taking and recording the drugs. Prescribed medication is individually dispensed on a week-to-week basis in bottles labelled with the type, dose, and time of medication. The system had been operating for less than a year at the time the study was conducted.

of their own medication from the day they are prescribed. At the same time, the need to comply with taking medications as prescribed is reinforced verbally.

- 3) to protect the public from tuberculosis infection by detaining the patient in hospital until his sputum or discharge is known to be negative for acid-fast bacilli on direct smear,

Standard Recommendations for Management of Tuberculosis:

The following summary is derived from: written information available in the hospital as guidelines for practitioners; statements from medical and nursing personnel consulted; and written information that is provided in pamphlet form intended for distribution to every patient. The text of the latter, entitled "The Treatment of Tuberculosis" is shown in Appendix 2.

Prescribed Medication Regimen: When a diagnosis of Tb is confirmed, it is standard practice to prescribe a combined regimen of three antituberculosis chemotherapeutic agents while awaiting results of sputum culture and sensitivities. This is consistent with recommendations by Weinstein (1975) and others that because drug resistance can develop within six to eight weeks when one drug is used alone, and in case of resistance to one of the drugs, triple therapy is used initially.

The standard regimen currently favoured includes two of the most effective oral antituberculosis agents - rifampicin and isoniazid - which are marketed combined in one tablet, Rifinah. In addition, ethambutol is prescribed, and is frequently withdrawn once it is known that the organism is sensitive to rifampicin and isoniazid. A side effect of isoniazid is peripheral neuritis, which is minimised by routinely prescribing Vitamin B₆ - pyridoxine.

Follow-up Appointments at Chest Clinic: Patients are required to present themselves at Chest Clinic at intervals of six weeks to three months throughout the time they are on medication. The appointment details are mailed to patients from the Chest Clinic at the time the appointment is made, and a reminder is sent approximately two weeks before the appointment.

Other Related Recommendations: 1) Promotion of Recovery - patients are advised against excessive alcohol consumption, because alcohol, rifampicin, and isoniazid are all toxic to the liver. Patients are informed that smoking lowers the body's resistance to tuberculosis and should be stopped or at least reduced. These recommendations are noted in the information pamphlet for patients. In addition, a prominent notice at the main entrance to the ward also warns against the health risks associated with smoking and requests that people don't smoke.

2) Protection of Others - hospitalised patients are instructed in the correct disposal of infected material, and advised to avoid close contact with visitors. Patients are also restricted from entering small enclosed spaces where there are noninfected persons, such as shops and the hospital canteen. The need to minimise droplet spread by covering the mouth when coughing and to dispose of sputum safely is communicated in the information leaflet.

Regimens and Recommendations Prescribed for Participants:

The therapeutic regimen and appointment schedule as documented in patients' medical records along with participants' interpretations of the regimen and behaviours expected of them are discussed, and presented in summary form in Table 2, p.83.

Although all participants in the study were initiated on a triple therapy regimen, at the time of the study, six had had ethambutol withdrawn, and were continuing on dual therapy. Two others were prescribed second-line drugs, because of resistance to first-line drugs. Seven patients were taking medications for

other disorders, such as hypertension, or diabetes, at the same time as antituberculosis medication. All participants stated that they were specifically instructed to follow the regimen and attend clinic appointments, but that there was less emphasis about other behaviours generally recommended.

As indicated above, recommendations about lifestyle to promote recovery and instructions to prevent the spread of disease are clearly set out in the pamphlet "The Treatment of Tuberculosis". However, eleven of the participants claimed that they had not received the pamphlet. Furthermore, in the experience of the patients who were interviewed information and recommendations other than those relating to prescribed treatment and clinic supervision were seldom given. These assertions are consistent with statements by half the participants that they had no instructions besides the need to comply with the regimen.

Advice to abstain from or reduce alcohol consumption, which will be discussed in greater detail in a following section, was not uniform, and while six participants stated they were so advised, others were informed that alcohol was not contraindicated. Similarly, patients were not as a matter of course advised not to smoke. In fact, although eleven of the participants were smokers, only four reported that they were specifically advised to stop.

Most participants reported restrictions that they were instructed to observe while they were in hospital to minimise the risk of infection, but only seven were able to describe measures recommended to protect others subsequent to their discharge from hospital.

In summary, participants were required to comply with prescribed medication regimens and with chest clinic appointments. Other behaviours generally recommended were not always specifically advised or reinforced. Practitioners verified this by stating that medication regimens currently prescribed are highly efficacious and can be depended on to effect a cure. In

Table 2: Prescriptions and Recommendations Received by Patients

NATURE OF RECOMMENDATION	MEDICATION REGIMEN				CLINIC APPOINTMENTS			OTHER RECOMMENDATIONS		
TOTAL WHO RECEIVED SAME	22				22			11		
SPECIFIC REGIMENS AND RECOMMENDATIONS (NOT MUTUALLY EXCLUSIVE)	Triple Therapy	Dual Therapy	Second line Therapy	Other Medication (not for Tb)	Chest Clinic	Other clinics/depts. for Tb	Other clinics/depts. (for other than Tb)	Promotion of Recovery	Protection of Others	Other therapy (e.g. diabetic treatment, physio)
TOTALS WHO RECEIVED SAME	14	6	2	7	22	3	6	6	7	3

the view of practitioners consulted, it was suggested further that the fewer adjustments patients are required to make, the greater the likelihood that they will comply with what prescriptions are made.

How the medication regimen is perceived: Triple therapy prescribed for a medium-weight male Tb patient is documented in medical records in the following manner,

Rifinah 750mgm mane a.c. (i.e. in the morning before food)

Ethambutol 1400mgm mane p.c. (i.e. in the morning after food)
Pyridoxine 25mgm

From the prescriber's point of view, and endorsed in the opinion expressed by some participants, the regimen is not demanding, needing attention from the patient only at one time of the day, around breakfast time. In the past standard antituberculosis regimens of triple therapy have consisted of daily injections of streptomycin, and isoniazid and PAS taken by mouth four times daily. The latter is an unpleasant bulky drug to take, that frequently causes gastrointestinal upsets. By comparison, the present regimen is greatly simplified as well as highly effective, and it is reported to be not as difficult to motivate patients to adhere to the regimen.

Nevertheless, the patient's point of view of the example of a regimen given above may differ from that of the prescriber. "Rifinah 750mgm" entails taking three tablets, two of one colour and dose (300mgm) and one of another (150mgm). He is instructed to take the first lot of tablets first thing in the morning, about half an hour before breakfast. After breakfast, he takes the remainder - three ethambutol 400mgm, and two ethambutol 100mgm, plus one pyridoxine tablet. In all, he must swallow nine tablets consisting of five different varieties and dosages, some before and some after eating. He has to continue to do so for some months, and depending on clinical progress, after ethambutol is withdrawn, to continue with the simpler dual therapy until at least one year of treatment is completed. If the patient hasn't had experience or knowledge of the previous regimen, and is unaccustomed to taking medication, he doesn't necessarily find this simple and undemanding. To one person, his cupboard (where he kept the medications) was "like a chemist shop", and another described himself as "a walking pill-bottle". Others commented negatively on the number and size of tablets they had to take, supporting assertions such as those by Hoover (1980) that the practitioners' and patients' perspectives on a single issue do not always coincide.

SELF-REPORTED COMPLIANCE BEHAVIOUR

Based on information obtained from participants and their families through in-depth interviewing, compliance is here interpreted as the extent to which self-reported patient behaviour coincides with specific prescriptions and related recommendations. Participants' explanations of their behaviour further uncover the meaning of compliance in the experience of patients.

Rates of Compliance:

Compliance with prescribed medication was higher than has been reported in certain literature (e.g. Dunbar, 1979). Seventeen participants reported that they took all prescribed medication every day. Of these, only ten took the medication always precisely as prescribed. Most instances of inaccurate compliance were unintentional, caused by forgetting, or misunderstanding the regimen. Several patients reported that they had taken their medications late on occasions, but had never omitted a day's dose, and a few admitted that they had forgotten completely a few times. One person always took all the tablets at the same time because he did not understand that they were scheduled before and after food. Two patients had run out of medication before their next clinic appointment, one of whom obtained an interim prescription. Another had been without medication for four days on two occasions, which is the most serious error encountered.

Two participants only deliberately altered the dose or the schedule, but never omitted a day's medications. One doubled the prescribed dose of pyridoxine "because it is good for you", and another took all drugs at the same time although he was aware of the correct schedule, "because it is easier to remember".

There was no falling off of compliance as the complexity of the regimen increased (when drugs for the

treatment of other disorders were added), or as the period of time since treatment was initiated was more prolonged. These trends are not consistent with those indicated by Fitzgerald (1976), but numbers are too low to permit inferences to be made.

Compliance with clinic appointments was generally high. The exceptions were a participant who deliberately failed to present himself at his first appointment, and did not contact the clinic, but he stated an intention to attend the rescheduled appointment. One forgot the appointment, but telephoned immediately to make another appointment. Three patients who were recorded in their medical records as having failed to keep an appointment had no recollection of this, and all kept rescheduled appointments. The one deliberately broken appointment for other than Tb follow-up was because of fear of possible hospitalisation at an inconvenient time. Only three participants reported compliance failure with respect to both the medication regimen and clinic appointments. It also emerged that the same people seemed to lack support and interest from their families in their treatment.

Compliance with proscriptive recommendations was generally lower than that with prescribed regimens. A similar trend has been noted in literature (Haynes, 1976), and indications are that the greater the extent and expected duration of behaviour change required, the less likely is full compliance.

Rates of compliance reported by participants in relation to prescriptions made are summarised in Table 3. The pattern of compliance with proscriptive recommendations compared with prescriptions suggests not only a falling off of compliance with the former, but that practitioners themselves place less emphasis on those recommendations.

Table 3: Rates of Patient Compliance in Response to Medical Recommendations²

		STANDARD MEDICAL RECOMMENDATIONS	NUMBER RECOMMENDED	RESPONSE OF PARTICIPANTS		
				Behaviour as recommended	Behaviour modified toward recommended change	No Change of Behaviour
Prescriptive		Antituberculosis Medication	22	17	5	-
		Chest Clinic	22	17	5	-
Proscriptive	Lifestyle	Reduce/ eliminate alcohol	6	2	4	-
		Reduce/ eliminate tobacco	4	1	1	2
		Protection of Others	7	5	2	-
Non Tb measures		Referral appointments	9	8	-	1
		Diet and other recommendations	5	3	1	1

Several possible reasons for findings that the extent of compliance with medications is high and did not fall off over time can be suggested. An important one is that participants became accustomed to taking prescribed medication daily and gained confidence in doing so correctly by being given responsibility for taking their own medication throughout the period of hospitalisation. While management of the regimen by hospitalised patients has been suggested as a strategy to improve compliance (Gill et al, 1981; Kellaway et al, 1975), no studies measuring effectiveness were located for purposes of comparison. At the same time, the need to "never miss" a day's medication was emphasised, often repeatedly, by practitioners, and was usually reinforced when patients were discharged home.

² No attempt is made to relate rates of compliance with demographic variables, because of small numbers of participants, and because inconclusive and contradictory findings reported in literature suggest this to be a fruitless line of inquiry (Becker, 1979).

Explaining Compliance with Therapeutic Regimens:

The illness experience and occurrence of particular symptoms appeared likely to have an effect in motivating compliance. Of seventeen who were seriously ill before the diagnosis of Tb was made, and particularly if they experienced haemoptysis (coughing up blood) or chest pain, the desire to be cured or the promise of a cure if they adhered to the treatment motivated continuing compliance. Three of those seventeen indicated a belief that the medication would control persistent symptoms, or prevent symptoms such as haemoptysis from recurring. Another three stated that a major reason that they complied was because they did not want to have to go back into hospital. The belief that compliance is a necessary condition of recovery and of remaining free of symptoms or further hospitalisation was expressed in comments such as the following:

"It's no good not taking medication...It's no good taking both medication and drinking beer...You get sick...you get sick and go back to hospital again..."

One man who asserted compliance with prescribed medications and advice to abstain from cigarettes and alcohol consumption described his position in this way:

"I made up my mind that when I went back to the clinic, if I got a bad report, I would say 'blow them'. And I would start drinking and smoking. So long as I am doing alright, I'll keep off them and carry on with the blasted pills."

The attitude expressed in the previous paragraph is supported by a study amongst glaucoma patients by Vincent (1971) who found that rates of compliance fell when expectations of treatment were not being met. An implicit practitioner-patient contract can be inferred, which is negated in the event of either party failing to fulfil obligations. The concept that has arisen from this phenomenon, the "therapeutic alliance", has received some recognition in literature (Paulen, 1981).

A participant who stated she was clearly instructed to comply with the prescription and warned of the risk of treatment

failure if she did not do so, did in fact acquire resistance to medications, and finally needed surgical resection of infected lung tissue. When informed of the need to return to hospital she answered:

"But how could I have Tb again? I've taken the tablets religiously...I was so very particular about taking the medications - and look where it landed me!"

By inference, assurances that the patient will be disease- and hospital-free provided he adheres to prescriptions and recommendations can be used not only to initially motivate, but also to sustain, compliant behaviour. A failure to maintain progress in spite of adherence may result in deliberate noncompliance or a sense of guilt or injustice,

To motivate compliance through a process of negotiation depends to a large extent on the experience of symptoms. There are indications in the literature that motivation to comply is more problematical in the absence of symptoms (Strauss, 1975). Six of the 22 participants were minimally ill or asymptomatic at the time when the diagnosis was made, and others became asymptomatic within a short time of therapy being initiated. Nine participants who were feeling well at the time of the interview gave such reasons for continuing to comply with treatment as that it was the doctor who "knew best" about such matters, that the prescription was "for your own good", and that one "ought to follow doctor's orders". It was a straightforward matter to some:

"I'll stick with the treatment...I made up my mind that whatever they said I was going to do, you know? They know best."

Another was bewildered that she still had to take the medications in spite of assurances that she was alright -

"I went to see him just for a check-up. But I got another prescription. But the doctor said, 'It's alright now'. But I still got tablets to take. They say - I thought they say - 'It's alright now'. But I keep on taking tablets. And I don't know why."

It seems that such assurances have the potential to encourage

the patient to abandon treatment, which is consistent with Mechanic's (1972) commonsense model to explain compliance failure. By this, the patient's actions are consistent with his current state of well-being or presence of symptoms, and in this case, assurances of desired response to treatment without reinforcing the need to continue taking treatment.

Another patient appeared to deny that she had Tb (and believed the diagnosis to be wrong) but nevertheless complied with the prescription, because she didn't want to be thought of as "stupid" in not adhering to recommendations.

In summary, adherence to a prescribed regimen over a long period of time is motivated and sustained by the desire to be disease-free, and particularly when the symptoms and experiences associated with the disease, including hospitalisation, are threatening or unpleasant. In the absence of such experiences, the knowledge and expertise of medical practitioners in most cases serves as a valid reason for complying with the prescription. An emphasis on the need to comply has provided additional motivation, and thus resulted in high rates of compliance in the study group.

Meanings of Compliance with Proscriptive Recommendations:

Compliance with recommendations to alter one's habits and lifestyles is much less straightforward than adherence to prescriptions.

Alcohol: Although most participants would occasionally drink alcohol, five were noted in the clinical records to have a high consumption of alcohol. Few reported that they were strongly recommended not to drink alcohol while they were taking Tb medication, but several were informed that it was inadvisable to do so. Those who drank little or no alcohol had no changes of behaviour to make. Others (four) stopped drinking of their own volition when they became ill, and so their behaviour change did not constitute compliance to a recommendation, as indicated by the following statement.

"They asked me if I drink. I said I used to, but since I've been sick I stopped drinking."

Of those who were advised not to drink (including those who had abnormal liver function tests when treatment was initiated), four who did try drinking alcohol experienced unpleasant effects. They found that the effects of alcohol were enhanced, or that alcohol and medication were incompatible. Comments made by participants suggest that patients in that situation have three alternative courses of action. They may decide to abstain from alcohol for the duration of therapy:

"I will take it easy for a year, so long as I'm on treatment. And once the treatment is over, I can start drinking again."

They may cease taking their medication in order to continue their way of life, although no participant admitted exercising this choice; it is sometimes problematic as one person observed:

"I know that a lot of them - the alcoholic types - are usually kept in a long time. Because you can't drink and take these tablets at the same time. It has really nasty side effects - I've been practising, and it doesn't work...so if you have an alcohol problem, they try and treat that too, and in some cases they may be successful. But these guys - they have no jobs, they usually live in doss-houses, and they've just got nothing except drink. So to rehabilitate them is a really hard job...They don't always want to be rehabilitated...But they don't always take medications, either."

A third course of action is to tailor the schedule in such a way that both medication and alcohol can be taken. One participant experienced ill-effects after drinking and recognised it was caused by the interaction of drugs and alcohol. As he still wanted to drink, he would take his medication very early in the morning on the days he intended to drink. He would also wait until the

discolouration of urine, caused by rifampicin, had cleared before he drank, believing that by then the drug should be out of his body. Another attempted, unsuccessfully, to negotiate with a physician for a suspension of therapy for a week or so to allow her to join in drinking at a series of social functions during that period.

Participants who were recommended not to drink and who experienced no unpleasant effects if doing so had then to decide to what extent to comply. The following comments suggest that their decision to accept or reject the advice depended on how valid they perceived that advice to be, and how easy or difficult it was for them to comply;

"I used to drink like a fish - bottles and bottles. Get drunk. Not every day, but when I used to go to the pub I'd have a good drink...I can't do that now that I'm on these. [Is it hard?] Oh I don't know whether it's hard - I think it's better for me... I still go down to the pub - I go down there and have a chat to my friends... but I hardly touch the drink."

A man with a serious alcohol problem with cirrhosis of the liver who was drinking during the interview declared:

"I'm not supposed to drink beer for the rest of my life...I had a bit of a liver problem. I used to drink quite heavily, I suppose. They told me not to drink for the rest of my life...I told the woman (from an alcoholics' association) straight - 'I'm not going to tell you lies. You'd know I'm telling you lies! But I'd be a liar if I said I wasn't going to drink when I get out of here'... 'But I don't drink nowhere near the stage that I used to. I just have a shandy, that's all. Fifty-fifty. I might have a couple at lunchtime, and that's it."

Tobacco: A similar process of balancing the perceived advantages of compliance with the recommendations made

and the social and personal consequences this will have for the patient takes place when advice not to smoke cigarettes is given.

One of several participants who had ceased smoking of his own volition when he became ill had this to say;

"It was funny, Before I had tried to stop once or twice, and never could, So I decided that I would never stop smoking, But this time, I got so crook I just knocked off, I suppose it was fright, or whatever."

Although some smokers who were advised to reduce or cease smoking complied with advice, others who did not gave a variety of reasons for their action. These included an implied reluctance to comply to an order, compounded by their enjoyment of smoking.

"They always suggest you cut it out. But they can't stop you from smoking. They can't stop you doing anything. It's up to yourself."

"I like smoking. Why should I have to stop? It's not sensible, and I can recognise that myself - but who said you have to be sensible all the time."

Some would acknowledge that smoking has harmful effects, but justified continuing to do so by pointing out that air pollution had similarly harmful effects. One who stated he needed to smoke for his "nerves", believed the alternative would be anti-anxiety medications.

"I do think it helps your nerves, you know? Smoking - I think if you get a bit agitated, a bit worried or something - I think if you could sit down and enjoy a cigarette it does you more good than harm, Better than going to the pill box,,,Because I don't believe in pills, you know?"

A few participants at some time had given up smoking but subsequently started smoking again, because they "wanted to", or "all of a sudden you get that craving - and if you take one, you've had it." Another

was urged by his wife to smoke again because "she reckoned I was crotchety at the kids all the time." Others had found that they were "eating all the time" and resumed smoking to keep their weight down. For others, personal experience of having complied with advice to stop smoking reinforced the promised benefits of doing so, and further reinforced compliant behaviour. For example, one recognised the financial benefits of not smoking:

"I find I have more money now, eh? I can buy things that before - I just had to scratch around. There's not much to a pension, by the time you've spent \$12 a week for cigarettes, and another \$12 on beer, there's lots of things you've got to do without."

Another felt healthier:

"Not smoking? I reckon it's good for you. More fitter, not coughing, or anything like that. When you are smoking you get up, and cough. Now - much better! Have a shower, go for a long walk."

Compliance with advice not to smoke (be it popular opinion or a specific recommendation) is affected by the desire of the patient, the perceived risks of smoking, the physiological effects of nicotine withdrawal, and the benefits of not smoking. All this takes place in a social context, which makes it more or less difficult to comply with advice. Some participants continued or resumed smoking because the people with whom they interacted did so, and it was an important part of their lifestyle. One described the extent to which she had to withdraw from her former social group in order to comply with those recommendations:

"I put it this way - I used to drink every weekend. Not every night - I didn't go to the pub. My husband's friends would come, and we would have some beer. And football season comes, and away we would go... But I don't go with them now. He goes drinking. I stay at home. I keep out of it because they all smoke. Maybe it's because I got Tb and I don't want to inhale all

that smoke again because it's not good for me. But I've learned not to go out,,,I say - I don't know why I should go to parties when I don't drink, and just sit there and watch them. And - I shouldn't be going there, watching what they do, saying things about them, because they are healthy, and I am not."

She admitted to craving for a cigarette from time to time, when household members smoked in her presence;

"They go outside to smoke - of course, I kick them out if they are smoking inside."

It can be inferred from the experience of participants that adherence to advice about lifestyle habits such as not drinking alcohol is seldom an act of submission to a recommendation or a prohibition. The patient makes a decision influenced by the degree of addiction, and the extent to which a change of behaviour will intrude on his lifestyle. The degree of congruence of the beliefs of practitioners and patients about the risks of persisting with potentially harmful habits, and the relative value placed on wanting to be "cured" and wanting to continue in one's preferred lifestyle, will also affect the decision. Barofsky et al (1979) have described the decision-making process as a balancing of the advantages of compliance against the impact on lifestyle and the quality of life.

It has emerged from the findings that the practitioner makes the recommendation, but the patient makes the decision as to what extent to comply, a process consistent with that described by Rosenberg (1979). The issue was clearly articulated by one participant:

"I do not necessarily want to be told what to do. But if they said, 'I advise you not to drink, smoke, or whatever - it is detrimental', and so on - then you can make your own decisions. You see?"

In order to make the decision, the patient needs to be informed of the benefits of adhering to

recommendations and the consequences of not doing so. This point will be discussed in depth in Chapter Seven.

Measures to Protect Others: The most important means of minimising risks of infection are hospitalising patients until sputum is negative, after which chemical isolation is maintained provided the patient continues to take prescribed medication. Although most participants understood the necessity for a period of hospitalisation, only two indicated that they had been made aware of legal obligations to remain in hospital until sputum is negative. One of these had a resistant strain of the organism and a consequent delayed response to treatment, and was informed of an obligation to remain in hospital only when the family attempted to negotiate discharge.

Most participants could identify specific restrictions associated with the period of hospitalisation with which they claimed they had cooperated. These included not entering enclosed spaces such as shops, and children not being permitted to visit. While the rationale for restrictions was understood by some, others asserted compliance without understanding the reason, as indicated by the following:

"In the [general] ward the kids were allowed to visit, but when he was in the Tb room they weren't. But I know - that's a law in the Tb room, but I don't know why."

Several believed it was acceptable to see their children provided they did so outside the ward. Some indicated they would go down and sit in the car, with their family, an action which suggests that the car was not defined as an enclosed space and therefore restricted. It is apparent from such comments that when patients did not correctly understand the necessity or rationale for restrictions associated with hospitalisation, even attempted conformity with those restrictions could be misplaced.

Participants who were aware and concerned to minimise risks of infection would go further than instructed, as for instance when one person who believed that diabetics were more susceptible to Tb instructed diabetic friends not to visit. A family who cooked the food preferred by the patient used to keep plates used by the sick person apart from other dishes, and to boil them, until informed by medical practitioners that the practice was unnecessary. The behaviour of some conformed to their beliefs about their infectious state:

"The first thing someone does who comes up to see you is to go and put their arms around you. And I would say 'No! Back off!' And it is a good thing. Especially when you know how easy it is to spread it, I'm sure you would take all precautions."

After discharge from hospital, participants understood that they were no longer an infection risk, even though most were aware that the disease wasn't yet eradicated,

However, the status of being noninfectious was taken by a quarter of the participants to mean that there was no longer a need to observe any precautions to minimise the risk of infection. Nevertheless, it is pointed out in the information pamphlet that the risk of infection remains until the course of treatment is completed. Measures necessary for the protection of others are limited to covering the mouth while coughing, and safe disposal of sputum. To many, no change in behaviour is required, as the following comment suggests:

"When I cough, I never cough on anyone. Well, it's manners never to. I mean, I never have in all my life. Have you?"

Of the few who admitted to habitually expectorating anywhere they happened to be, one claimed he had not been instructed on correct disposal, and continued to spit anywhere. Another asserted compliance with instructions about correct disposal, adding

"I always do that now - you only need an experience like this one. When I think...well, that's what I do now,"

Conformity to measures to protect others, then, appears to be either because it is consistent with social mores and life habits, or a continuation of practices learnt while in hospital, rather than a response to specific instructions about precautions in the community context. In most instances, practices were consistent with those desired, but the number of participants who stated that they believed that no precautions were necessary after discharge suggests a need to explicitly reinforce or provide instruction about measures to protect the public. Participants whose recovery was complicated by acquired resistance, necessitating alternative medication regimens and surgery, were much better informed of the need to observe measures to minimise the risk of infection.

SUMMARY AND CONCLUSIONS

The data reviewed in this chapter has indicated that the regimens and recommendations patients receive are less uniform than may be expected from standard procedures for management. It can be seen that to measure behaviour objectively against standard practice, without specifying precisely what prescriptions and recommendations were made to participants of the study, could give rise to misleading rates of compliance.

The relatively high rates of compliance to prescribed medications and with clinic appointments that were found in this study may be attributable to the system of "Individualised Patient Medication" in use in the Tb ward, and to the fact that the importance of adhering to the regimen is reinforced verbally by practitioners. An additional perspective provided by patients' explanations indicates that compliance with prescriptions is recognised as a necessary condition to controlling symptoms and achieving a cure,

However, there is a falling off of compliance rates when recommendations are proscriptive as compared with prescriptive. It is

seen therefore that compliance is not a uniform response to medical orders, but is affected by a number of moderator variables. Patients' explanations suggest that compliance with recommendations to modify or eliminate a behaviour generally requires greater life-style adjustments. A process of balancing perceived advantages of compliance with recommendations, against social and personal consequences for the patient, occurs. New events or occurrences can lead to a re-evaluation of earlier decisions as to the extent of compliance, and factors in the social context can affect patients' ability to comply. The position that compliance to prescriptions and proscriptions are behaviours of different orders is strengthened by comparing within the same study group self-reported compliance behaviour to both forms.

An examination of compliance with measures to minimise the risk of infection raises questions about the appropriateness of the term "compliance" in view of its literal meaning. It is clear that although behaviour in many instances conformed with that desired, patients' explanations inferred that they were acting in a manner consistent with social mores and personal beliefs, rather than in response to recommendations.

An interpretation of compliance from within the experiential frame of reference of patients indicates that the phenomenon is more complex than, as the term implies, a submission to medical prescriptions and recommendations. It is apparent that the activity of patients is not restricted to carrying out orders and recommendations, but that they also make judgements and decisions about the importance and benefits of doing so. Furthermore, significant others, be they family members or friends, influence both decision-making and compliance behaviours. These issues will be explored further in the following chapter, where patients' experiences in complying in the domestic environment are discussed.

CHAPTER SIX

COMPLIANCE IN THE DOMESTIC ENVIRONMENT

Patients who participated in this study were discharged home after having spent between four and one hundred and one days in hospital, with around one month being the modal period of hospitalisation. During this time, patients managed their own medication regimens from the start, and were responsible for continuing to comply with the treatment plan after discharge. This chapter looks at continuities and discontinuities that patients experienced with the change in environment. There were particular times or occurrences that participants identified as barriers, potential or actual, to compliance at home. Patients responded in a variety of ways to these factors and events, with some developing their own strategies to assist them in complying, or in monitoring their own compliance. In this context, it became evident that other members of the patient's household frequently have an influence on compliance behaviour, and at times supervise or manage the regimen for the patient.

The focus of this chapter is on compliance with the medication regimen, but when discussing compliance in the context of the family, other prescribed recommendations are reintroduced.

CHANGES ACCOMPANYING DISCHARGE FROM HOSPITAL

There are obvious adjustments to be made from a hospital environment, where patients' medications are accurately dispensed in weekly amounts and patients have few concerns and responsibilities other than taking medication, to a domestic situation where the medication regimen becomes just one concern amongst many concerns and responsibilities.

Changes in Patient Status:

The period of hospitalisation forms a definable passage from one social identity to another, and as such constitutes a "status passage" in the patient career in terms of the concept described by Twaddle et al (1977). Marking the end of that status passage, discharge home signifies definite progression toward the end point of the career, which is recovery and completion of treatment. A crucial change in patient status is that he is no longer considered to be an infection risk to the public. Participants of this study seemed to understand the need for hospitalisation to protect their families and the public from infection until antituberculosis therapy had rendered them noninfectious. Explanations given are reinforced by the standard procedure of taking specimens of sputum and gastric washings or other discharge for microscopy at monthly intervals, until sputum or discharge is negative for bacilli on direct smear. Only then are patients discharged home, as one participant reported explaining to a fellow-patient newly admitted:

"I told her - you had better settle in. Because I tell you, you know, you will be here a month. By the time they start the drugs, and then do the first repeat sputums to check you are clear - and it takes a month for the drugs to take effect. The sister told me that..."

The need for infectious patients to be isolated from the public is recognised by some patients, particularly when measures available to enforce detention are made known to unwilling patients.

"They didn't tell me that, but I heard them say to others about getting the police to pick you up and bring you back, so you can't be a nuisance to everybody else."

When asked to explain further, he said:

"Well, it's logical, isn't it. You are contagious, aren't you. I mean, you can pick it up from breathing, you can pick it up from touching something."

In the course of the inpatient experience, participants understood that only when they were no longer an infection risk were they discharged. One of several participants whose discharge was delayed explained:

"They were trying to get me out of there a full month before I finally got home! I had to get clear of sputum, you see. The first two were clear, and then the last one I had a germ. I had to stay another four weeks after that. But - ah - it wasn't worrying me in the least. So long as I was getting better, that's all I was interested in...it was a case of passing it on, more or less. We were carriers, and could pass it on. That's why we were in there. [Was he still able to pass it on?] No, no, I wasn't allowed out until I couldn't. As a matter of fact, they told me that I was one of the few (in this area) people wouldn't be able to get it off."

Discharge from hospital marked a change in patient status not only from being infectious to noninfectious, but also signified changes in the patient's social status. Hospitalisation isolated the patient from the public for their protection, and at the same time removed him from normal family, occupational, and other social responsibilities. Along with discharge home, participants resumed to various degrees those responsibilities from which they had been exempt. However, discharge did not absolve them from their responsibility as patients to continue to comply with the therapeutic regimen. In terms of Parson's (1951) sick role theory, the ambulatory Tb patient has a qualified role to the extent that the obligations of the person to cooperate with the treatment process in order to get well are no longer complemented by privileges of being exempt from normal activities. In only four instances did participants continue to be excused from household and occupational responsibilities after discharge. Seven resumed full household responsibilities on discharge, and two returned to work the day of discharge, while others gradually resumed social activities.

From such comments as the following made by participants, the possibilities of not complying with the therapeutic regimen are higher in the domestic environment than in hospital:

"In the hospital environment, one doesn't have many opportunities to forget. But at home there is every possibility."

Participants identified a number of factors that exist in the hospital environment to facilitate compliance. For one, being removed from normal social activities, inpatients have few responsibilities other than taking medications, and there is little to distract them. Nursing staff regularly check informally on whether patients have remembered to take their medication, and with the pharmacist, monitor (without supervising) the administration of medication. Patients support and remind one another, and become accustomed to taking medication in the context of a daily routine in the ward. After discharge, the patient needs to continue to follow the regimen as prescribed without these supports and facilitators.

In respect to compliance behaviour, discharge from hospital is clearly seen in relation to the status passage. Difficulties patients may experience in making the transition from the status of inpatient to that of ambulatory patient in relation to compliance with the therapeutic regimen were recognised by practitioners, and for this reason the system of Individualised Patient Medication was introduced. Even so, nursing personnel continue to emphasise the importance of compliance at the time of discharge, according to nurses consulted and comments made to that effect by most participants:

"When I left, she told me not to overdo things - to take it easy. And to MAKE SURE I DID NOT MISS MY TABLETS. She emphasised that."

This constitutes an implicit recognition of the event of discharge from hospital as signposting the status passage, and in accordance with the notion of van Gennep (1960) there is a recognised need for practice to facilitate the transition to the new status. Whether or not practices presently employed are sufficient to enable patients to make that transition to the status of ambulatory patient, which includes successful

compliance in the domestic environment, is explored in the next section.

Barriers to Compliance in the Domestic Environment:

The majority of participants experienced and/or perceived factors in the home context that constituted barriers to their compliance with the regimen, some identifying up to five potential or real difficulties. Four participants only perceived no potential problems, two of whom had had tuberculosis previously, with documented histories of previous compliance failure. Two had not correctly understood the regimen or schedule, and the most serious omission was committed by one of these.

The most frequently identified barrier was forgetfulness, associated with being distracted from an intention to take the medication as when the telephone rang, or somebody needed attention. The time of discharge from hospital was identified as a potentially difficult time in retrospect, until one's daily routine was organised in the home context. Variable work hours and shift work likewise increased the probability of compliance failure, because of a disturbance in routine. In fact, several reported instances of omissions in taking medications were attributed to changes in work hours and in being away from one's home and routine for a few days. Some participants expressed concern that the longer the treatment went on, the more difficult it was to remember. On the other hand, others indicated that as time proceeded, taking medication became as much a part of habitual daily activity as to be "like cleaning your teeth." Small numbers identified factors to do with the medication and regimen as potentially interfering with compliance, including: a dislike of taking medication of any kind; occurrence of side effects alone or in interaction with alcohol; no previous experience of taking medications; perceiving the regimen as difficult; and doubting one's own ability to correctly follow a difficult regimen.

In addition, eight patients commented on the way in

which medications are dispensed. Because follow-up appointments at out-patients clinic are required only every two to three months, patients are supplied with fresh prescriptions for that period of time. Most frequently, patients were supplied their medication in large containers, which a number found cumbersome. Further, they were unable to monitor their compliance by checking the amount of remaining medication. Several participants were bewildered because one kind of medication ran out before others, or different quantities were remaining at the time of the next clinic appointment. While some were certain they always took their medication, others began to wonder if possibly they had omitted doses without realising it.

Remedial Action and Strategies to Facilitate Compliance:

Of the participants who did omit on occasions to take medication at the prescribed time, because they forgot or were distracted, most expressed concern about the possible consequences of doing so. Those who reported that they forgot to take Rifinah before eating either took it after food rather than be without, or waited until the next meal to take it before food then. One explained that she had based remedial action on experiences in hospital when she had been fasting while undergoing investigations, and had been instructed to take medication at midday. Otherwise, according to participants' statements, there was no explanation or discussion with practitioners about the rationale for the prescribed schedule, nor what remedial action was appropriate in the event of omitting a dose.

Of those who were distracted after breakfast and didn't take the tablets then due at the time prescribed, half took them as soon as they remembered, whatever the hour, rather than omit a day's dose. Another took twice the prescribed dose the following day to catch up, and the remainder didn't worry, but resumed the following day. Only three patients who had omitted some or all of a day's medication were unconcerned, while concern was indicated by the majority in that they had taken remedial action, and further, several asked for assurances from

the researcher that the action they had taken was appropriate. In those instances, the researcher's response depended on the patient's circumstances, e.g. if a clinic appointment was imminent, the patient was advised to raise such questions with practitioners there. As the following comment indicates, anxiety was experienced by some about consequences of omitting medications:

"I missed twice, and I thought - 'I have to work out some system, to make sure that I don't miss it...I've been trying to work it so I don't miss again.' But I catch up during the day. Is that okay?"

In addition to taking action to remedy actual events of compliance failure, half of the participants developed strategies for themselves in order to minimise the risk of omitting medications. Deliberate and at times complex actions taken by patients to enable compliance indicate that the illness is perceived by them as an "occupation", in which they work toward recovery, as described by Herzlich (1973).

Most participants agreed that they seldom had difficulty remembering to take medication first thing in the morning, but the likelihood of being distracted and forgetting increased as the day proceeded. Strategies developed by eight participants were based on that factor. For example, several would take all of the medication containers out of the cupboard where they stored them first thing in the morning, and put them away one by one only after they had taken medication. Others used to dispense the day's tablets into a small receptacle first thing in the morning, to serve as a visible reminder to take the medications.

Several participants developed methods of monitoring their compliance. Said one:

"After a while, you get into such a habit that there would be no way I could guarantee that I had taken them. Only by going back and having a look and counting the tablets...What I have done is to take the bulk of pills and allocate them on a weekly basis into another container so I could look at them and count them, see how many were left. And so I could say, I have obviously taken them today."

Four patients had adopted this method described to monitor compliance, and a fifth kept a notebook in which she recorded when she had taken her medication.

A small number facilitated their compliance by dispensing all medication for the day at the one time, and by monitoring compliance in the manner described above. The use of terms such as "religiously" to describe their behaviour, or "ritual" to refer to the strategy suggests the concern of those patients with their compliance with the regimen.

Of the remaining participants who perceived or experienced barriers to compliance but did not develop strategies for themselves as those described above, three depended on a family member to assist them. For two patients who had other serious or disabling diseases, medication therapy had become for them a preoccupation. Others suggested that it was sufficient to keep the medication in an obvious place to serve as a visible reminder, such as beside the bed, or next to the breakfast things, although the presence of children in the house precluded this for some. A number indicated that they made a conscious mental effort both to remember to take medication and to recall if they had in fact taken them, or that medication taking was tied into daily routine.

Figure 3 summarises participants' perceptions of barriers to compliance in the domestic context, and strategies developed to facilitate compliance in response to perceived barriers. Self-reported compliance behaviour shows a decline when such action is not taken nor potential difficulties perceived.

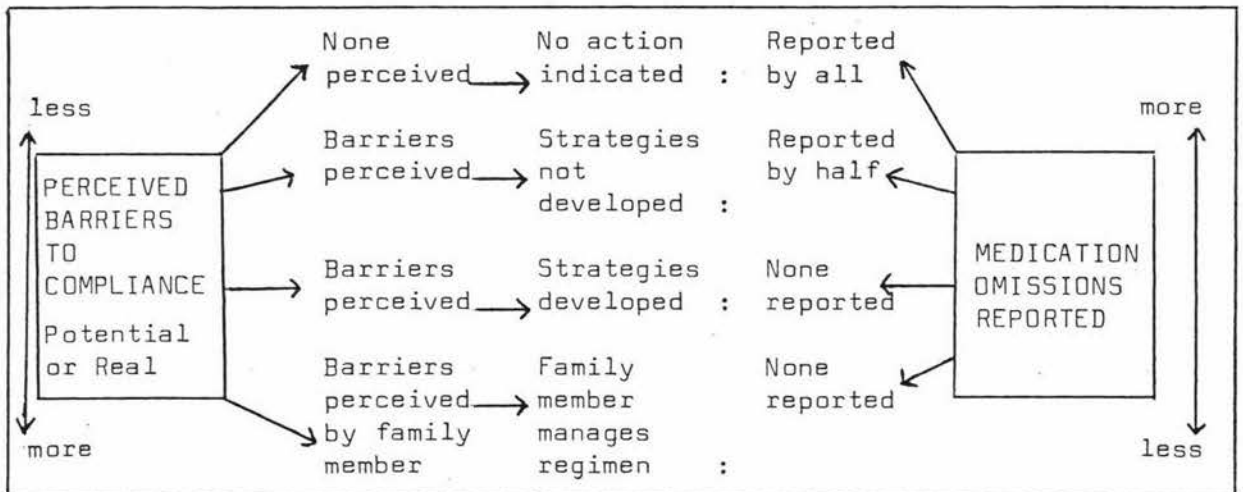


Fig 3: Patient Compliance in Relation to Perceived Barriers and Response

The finding that compliance was high amongst patients who developed reminder or monitoring strategies to assist them to comply is consistent with that of a study amongst Tb patients by Hecht (1974).

It needs to be emphasised that potential barriers to compliance in the home context were identified or experienced by patients only after discharge from hospital. That is to say, according to patients interviewed, they were not made aware of such possibilities prior to discharge, but only warned not to omit medication, and therefore were not prepared as to what action would be appropriate to prevent or remedy omissions. In the same way, patients were not assisted by practitioners to develop strategies to minimise the risk of omitting medication, and in fact only one participant reported that he had developed a method while in hospital. The remaining nine did so after discharge, either in response to experiencing difficulties in complying at home, or because they or a family member were anxious lest an omission occur. All who did so reported total compliance and satisfaction with the strategy developed.

It is inferred that participants who developed for themselves strategies to facilitate compliance were already motivated to comply. Patients who did so represent both male and female, and a spread of ages, ethnic groups (except Pacific

Islanders) and socioeconomic levels. While there is agreement in literature (e.g. Becker, 1979) that demographic characteristics are not associated with compliance, this finding suggests that neither are they associated with motivation or the development of facilitating strategies. Participants' explanations of what motivates them to comply with the medication regimen are presented in Chapter Five (pp.88f.). Motivation is further reinforced by practitioners emphasising the need to comply with the prescription, but findings of this study suggest that such warnings are not in themselves sufficient to enable patients to comply. One participant put it this way:

"The point was made that if the routine was broken you could develop a resistant strain, and that would be even more difficult. But - what constitutes a serious break in medication? Is it missing a component one day? Or a week?...I think one could easily miss one of the components for one day. If that is a serious risk then that's an area which someone ought to be providing a more effective method than the individual provides for himself."

While this particular person had developed a method of monitoring his compliance in response to potential difficulties perceived, there are indications in the study that patients who perceive no problems in complying, and therefore do not develop facilitating strategies, are more likely to experience compliance failure. This shows similarities to Hart's Inverse Care Law (1971), which states that those in most need of medical care receive the least. In respect to compliance, those patients who are very conscious of the need to adhere to the regimen and motivated to do so, have least need of strategies to assist them, but are most likely to develop the same. A need is indicated for practitioners to pay particular attention to patients who perceive no difficulties, and to assist them to identify potential barriers and develop strategies. The inverse relationship is shown in Fig 3 (p.108).

INFLUENCE OF THE PATIENT'S FAMILY ON COMPLIANCE

The findings of the present study indicate that not only is the household affected by the individual's illness, but that family members implicitly support and sometimes actively participate in the patient's adherence to treatment. This supports indications by Becker et al (1975) that family members have an influence on compliance. However, most supportive evidence in literature refers to the influence of mothers on children's compliance. The position is further strengthened here by findings that nondependent persons are also influenced by family members.

Participation of Family in Compliance with Medication:

Three patients in the study group lived alone, and along with another five, whose family apparently were uninterested in the treatment plan, were of necessity totally responsible and self-reliant in complying with the regimen. Another nine participants reported that although they personally retained responsibility for taking medication, the family was generally supportive, showed concern for their well-being and recovery, and would occasionally remind them to take the drugs. The positive effect a supportive family can have was expressed by a participant in this way:

"If I were not sufficiently fortunate to have a concerned wife I might quite easily have got into a casual attitude toward, or not been aware or frightened into, taking care."

The remaining five participants explained that a family member actively participated in reminding or assisting them in adhering to the regimen. Of these, the wife of a man who had a residual poor memory as a result of having tubercular meningitis, would frequently have to remind him to take the medications. The six year old daughter of another was said to remind her mother every morning, and sometimes to put the day's tablets into her hand. The spouses of three patients had taken over the management of the regimen, as one explained:

"Every morning when I wake up, before I get up from my bed, my husband brings, and says 'There's your tablets, and your cup of milo,' Every morning, no fail."

Findings of this study are that some two-thirds of participants enjoyed the implicit support or active participation of family members in their compliance with the treatment regimen, and that patients expressed appreciation of family assistance. According to participants' statements, this developed spontaneously, without encouragement from practitioners, in that family members were not included in practitioner-patient interactions, nor was their cooperation in assisting the patient to follow treatment elicited. Evidence of family participation supports Becker's (1979) premise that the potential of enhancing patient compliance by involving family members is significant, though seldom utilised. The more serious instances of compliance failure that participants reported (as when several days' medications were omitted) occurred amongst patients who did not have the support of family. By implication, there is a place for practitioners to actively encourage the family to be involved in the treatment process, as a strategy to enhance patient compliance. In this way, patients whose families do not spontaneously involve themselves in assisting the individual to comply could be more likely to benefit from the support that other members of the household evidently provide.

Cooperation of Family to enable Compliance with Clinic Appointments:

Although most participants were able to travel independently to clinic, a quarter of the group were dependent on a family member to transport them to clinic. In one case, attendance daily at physiotherapy entailed the spouse taking time off work to transport the patient. A family member who provided transport is liable to the same costs of time and work loss, as well as transport costs, as the patient. One explained:

"He has to take me. But I say -
 'You had better go away for a while,
 a couple of hours or so.' It takes
 that long, or more, you see."

Only one participant, however, perceived difficulties in complying with clinic appointments for these reasons. Most indicated that the infrequency of appointments kept the cost and inconvenience within reasonable limits, and therefore the family was willing to cooperate on those occasions.

Effect of Family on Compliance with Proscriptive Recommendations:

Evidence has been presented in the previous chapter that the extent of behaviour change associated with proscriptive recommendations, particularly of lifestyle habits, is greater than compliance with prescribed medication regimens. In the same way, while family participation in the medication regimen will at most involve reminding, or administering the tablets, cooperation with other related recommendations may require household members to modify their own lifestyle.

For instance, the family of one ex-smoker from the time of the illness were permitted to smoke only outside the house. One man voluntarily gave up tobacco to protect his wife from smoke, and insisted that no other family member or visitor smoked in the room she was in. Spouses of another two ex-smokers, on the other hand, continued to smoke in their presence, even though one patient had severe chronic lung disease (as well as Tb), and the other craved cigarettes from time to time. Both of these family members acknowledged that their continued smoking was beneficial neither to themselves nor the patients, but were not motivated to give up.

Participants did not comment in this vein about the effect of others' behaviour on their compliance with advice to limit alcohol. However, the observation of a few that it was more difficult abstaining from alcohol while those about them were drinking imply that compliance with recommendations not to drink is facilitated when those in close contact likewise are not drinking.

No participant made any mention of family members motivating or assisting in the maintenance of compliance by verbal encouragement. At the same time, comments were made by both participants and practitioners, in response to the interviewer's questioning, that practitioners did not encourage or elicit the cooperation of family members to assist the patient to modify lifestyle habits.

Two of the patients who were diabetics were proscribed a range of foods as part of their treatment. Compliance of one with the diabetic diet depended to some extent on his wife conforming with instructions while preparing meals. The other abandoned meal preparation responsibilities, as cooking constituted in her experience too great a temptation to non-compliance. In both of these instances, compliance with diet necessarily involved family members.

Involvement of Family in Caring for the Patient:

Little emphasis was placed on the need for the patient to rest more than usual, or follow nutritional advice. Exceptions were when the person had been seriously ill, or response to treatment slow or complicated. Three women who had extensive disease were relieved of much domestic responsibility by their families, as one explained:

"They just told us when she came home to make sure she continued to take the medication, to take plenty of rest, and so on. We don't let her do too much. Like, I'm a businessman, and I can work at home, and we all help out to make sure she doesn't overdo things."

At the time the interviewer arrived he had been doing the laundry, and a daughter was preparing the meal.

In spite of practitioners' assurances to the contrary, the families of some patients believed that adequate rest and nutrition were important for recovery, and acted appropriately. According to the wife of one patient:

"I think his biggest adjustment is to eat better. He has never been particularly interested in food...When he came out of hospital I would prepare breakfast for him and leave it out for him, otherwise he wouldn't bother...Now that he is better, he is slipping back into his old habits, if left to his own devices."

Another of the patients who also was encouraged by family to adjust living patterns had this to say:

"The biggest change once I got home was the wife telling me what I wasn't allowed to do! Ha! I wasn't allowed to work too long, I had to rest every afternoon. I don't know where she got it from! Even now (ten months after hospitalisation) she will say - 'Hey, you've done enough. Get in here and rest.'"

It is evident from participants' explanations that when the family believes that caring modalities are important to promote recovery and health, any recommendations made involve the household as well as the patient. Compliance with advice given or elicited depends more on the action of family members with passive cooperation of the patient, and not on the action of the patient alone.

Further evidence that family members interest themselves in the patient's illness and treatment is provided by the extent of their participation in the study. Other household members of eleven participants took some part in at least one of the interviews, with six participating to a major extent, either in dialogue with the patient, or interpreting at times if the patient's English was limited. Of the remainder, three lived alone, and six were alone in the house at the time of the visits. In only two instances were family members unwilling to participate.

In summary, it is evident that families have an influence on patient compliance. This is so even though the families of patients were seldom included in interactions between

practitioners and patients, and their cooperation in assisting the patient to follow the treatment plan was not elicited. The greater the effect on lifestyle necessitated by conformity to advice, the more family cooperation is required to enable patient compliance,

SUMMARY AND CONCLUSIONS

The time of discharge from hospital signifies progression along the patient career toward recovery. The status of being potentially infectious and needing hospital care for his own sake as well as for the protection of others is changed to that of an ambulatory patient, who is not considered an infection risk provided he complies with the treatment prescribed. Measures employed by practitioners to facilitate the transition in status consist mainly of giving patients responsibility for managing their own regimen while still in hospital, and in reinforcing the need for continued compliance at the time of discharge.

Participants perceived or experienced certain factors in the domestic environment which didn't occur in hospital, that potentially interfered with compliance. The most important was forgetting, or being distracted. Times that were associated with a greater likelihood of error were when one's daily routine was disturbed, such as around the time of discharge, when work hours change, and being away from home. Although patients were accustomed to taking medication by the time of discharge, there is no evidence that patients are prepared to anticipate such problems, or to prevent or remedy them. Nevertheless, about half the participants did develop reminder and/or monitoring strategies to facilitate compliance. Together with patients whose families managed the regimen for them, these participants reported much higher rates of compliance than those who did not develop such strategies. Omissions were made more frequently by participants who neither perceived potential difficulties nor took remedial action, and who did not have supportive families.

Even though family members were not included in the treatment process by practitioners, findings of the study were that in about two thirds of cases, patients' families were generally supportive, assisted adherence, or actually managed the medication regimen for

the patient. An examination of the ramifications of patient compliance with proscriptive recommendations and other health care advice further indicates that patient compliance depends to varying degrees on the active cooperation of family members.

It is concluded from the generally high rates of compliance reported together with comments made by participants, that practices currently employed to ease the transition of the patient from inpatient to ambulatory status, are helpful. However, through exploring with patients their experiences after discharge, it is evident that those practices are not sufficient to prepare patients to meet contingencies likely to occur in the domestic environment. Participants who reported fewest errors tended to be highly motivated to comply with the treatment plan, developed strategies to facilitate or monitor compliance, and often enjoyed the support or assistance of their families. Patients whose families do not of their own initiative offer assistance, and patients who do not perceive potential difficulties in complying, are at greater risk of compliance failure. By implication, practitioners can take action to improve compliance by encouraging the family to be involved. Furthermore, the patient with his family can be assisted to identify potential barriers and to develop appropriate strategies to facilitate compliance before discharge from hospital.

CHAPTER SEVEN

PERCEIVED PRACTITIONER CONCERN AS A FACTOR IN COMPLIANCE

After discharge from hospital, continued compliance of Tb patients with the prescribed regimen is seen as essential for the control of the disease as well as to the recovery of patients. It was assumed that health care practice would therefore be directed toward preparing and assisting patients to adhere to regimens. This chapter describes the extent of concern with compliance that patients perceive practitioners as having. The picture that emerges is one of variation not only between different practitioners, but also with respect to the several domains of compliance. The central issue in this discussion concerns the taking of medications. This is interpreted in relation to the extent and kind of information provided about the treatment plan, as reported by participants, as well as evident interest shown in compliance in subsequent contacts with practitioners. When considering compliance with lifestyle modifications and measures to protect the public, there are indications that actions of practitioners are not always consistent with their verbal recommendations. Out-patient clinic arrangements are considered as a factor in encouraging compliance with appointments.

CONCERN WITH COMPLIANCE WITH MEDICATION

Patients need to be informed about prescribed medications in order to be able to follow the regimen correctly and responsibly. Redman (1980) pointed out that patient teaching neither motivates nor enables patients to comply, but at the same time, it is not possible to comply without some knowledge (cf Becker, 1979). The emphases and extent of patient teaching as perceived by participants is considered in relation to expressed needs for information to be able to correctly adhere to the regimen.

Information about the Regimen:

The majority of participants agreed that nursing personnel were the main sources of information, although medical practitioners would add to or reinforce information. Participants' impressions that the information they received largely consisted of instructions as to how to take the regimen, and that teaching was carried out at the time they were supplied with their drugs, was verified by nursing personnel. Typical experiences were:

"She came in and told me to take this at this time, this and this at that time, never to miss, and sign here. Didn't say why. And if not, what."

The nurse who takes responsibility for patient teaching stated that patients are instructed in the context of explaining about the regimen, with the need to "never miss" being emphasised. Not a great deal of time is spent on teaching, and there is no structure or record of what teaching is carried out. Additional instruction may take place if patients initiate it, but is not planned. Group discussion or teaching does not take place, because numbers of English-speaking patients are too few to make it worthwhile. Family members are not instructed in the regimen or the need for compliance, although, as has been pointed out in the previous chapter, the influence of family on patient compliance can be considerable. Participants indicated that the style of teaching did not encourage dialogue or discussion. In the description of one, "The nurse read her little lecture..." However, patients found that practitioners were generally approachable, and would give any information requested. In one patient's experience:

"..... [the nurse] told me that. She has a book. She tells you anything. She doesn't keep anything back, tells you anything you ask... There were certain patients who were in there when I was in there the first time. And we were most interested..."

On the other hand, another patient observed that:

"...they should have come back and said 'Now, are you quite sure you have got it right?' It would have only taken a couple of minutes. If you are not sure, you would have to go and ask - 'Is this right? What do I do?' And you always feel embarrassed. I think it's much better if the approach was from the other side."

The amount and range of information a patient received, therefore, depended on the initiative of the patient rather than on the needs of patients as assessed by practitioners.

Barriers to access to information: Several factors emerged from the data as impediments to patients taking the necessary initiative. Chief amongst these is difficulty in communicating. Although cross-cultural issues weren't pursued in this study, there is evidence that patients whose English was limited and whose cultural background differed from that of practitioners, had particular needs that may not have been met. For example, most participants agreed that information about the schedule and the need to comply were given clearly. Of two patients for whom instructions were not clear, a Pacific Islander misunderstood the schedule because English was limited, and has continued to take the correct medication at the wrong time, and the other, a Maori, admitted being too shy to ask for clarification. Relatives of the former patient explained that they had made themselves available at any time for language interpretation, but had never been called upon for that purpose. On the other hand, the family of another Pacific Islander with limited English took the initiative when they visited in seeking out ward staff to verify instructions and progress reports. Practitioners themselves drew attention to difficulties in having bilingual relatives in the ward outside visiting times, on occasions when translation services were required, and therefore tended to call on bilingual domestic and other staff when necessary.

Other than language and cultural barriers, the manner of certain practitioners had the effect of discouraging several patients from seeking information. Explained one:

"He is probably a very good physician, but he really doesn't have much of a bedside manner. I find it extremely difficult to talk to him, and he really doesn't have much to say at all, even if you ask."

Another commented on the apparent busyness of staff:

"In hospital, dear, they don't tell us everything. Because they are so busy with other patients, you know?"

She did not discuss an issue worrying her with the public health nurse because

"She was in such a hurry that morning; she didn't stay long, dear."

Haynes (1979b) has indicated that fixed content teaching methods have little effect on compliance behaviour, and therefore a willingness of practitioners to provide information to patients according to their particular needs is appropriate. However, findings of this study suggest that certain factors militate against patients taking the initiative, with the result that needs may not be expressed and therefore remain unmet.

Content of Teaching:

All participants understood that the purpose of medication was for the treatment of Tb, and that they needed to follow the regimen as prescribed. A number of patients stated that information other than regimen instructions was seldom given. Two patients who were still in hospital were also questioned, because, since the treatment was newly commenced and few intervening occurrences had taken place, accuracy of remembering would be facilitated by recency of events. They

indicated also that they had been instructed on how to take the medication, but not in the rationale behind it.

Erroneous beliefs about treatment were more likely in the absence of being given explicit and correct information. A number of participants had come to erroneous conclusions about the treatment, such as a belief that the medication would only suppress the disease. Said one:

"The Tb is not cured. The Tb never becomes cured. It's only arrested - just put to sleep."

Some of the beliefs patients held about the treatment were unlikely to affect compliance with the regimen, e.g. three who were informed that pyridoxine was prescribed to counteract side effects of one of the drugs assumed that one to be ethambutol (because it was taken at the same time as the pyridoxine). One man who had been prescribed lorexane for the treatment of scabies believed it was treatment for a drug-induced skin rash.

More serious confusion came when the patients were taking medication for other conditions at the same time. For instance, one man believed that ethambutol was for the treatment of hypertension. He claimed he always took it daily, but also stated that he would adjust his antihypertensive medication himself according to how he was feeling. Erroneous beliefs about the purpose and action of medication potentially interfere with compliance, and may also cause unnecessary anxiety. One patient was worried that the orange discolouration of urine, caused by rifampicin, was because the medication was "burning out" the disease, an idea he found worrying.

No participant understood the reasons why Rifinah was scheduled before food, and the other medications after food. As has been suggested in Chapter Six, a lack

of such information makes it more difficult for ambulatory patients to appropriately remedy omissions in taking medication at the prescribed time. These findings support conclusions in literature that patient knowledge is necessary to enable compliance to take place (Becker, 1979).

The occurrence of side effects, as indicated in literature (Fitzgerald, 1976), did not interfere with compliance. However, participants asserted they were not warned of what possible drug side effects they may expect. A third of the participants experienced such side effects, ranging from symptoms that settled spontaneously - nausea, headache, skin rash - to severe skin reaction or severe headache that necessitated the reduction of dose or withdrawal of offending medication. Having experienced side effects, those patients became aware that they were drug-induced, but even then it was not always clearly explained:

"They were worried that the headache may be a side effect from the medication...It was never explained. We came to that conclusion, worked it out for ourselves."

Some participants inferred what possible side effects there were from the interest of practitioners in certain symptoms:

"I would think - what are the side effects. And they don't usually tell you - they ask you 'How do you feel?' And you tell them...They ask if you have any nausea or vomiting. So you think - that's a side effect!"

It is implied from comments such as these that when specific information is not provided to patients, the suspicion or experiences of untoward symptoms can be unduly worrying. While explanations are given in due course to some, others seek information or reassurance

about symptoms. Otherwise, because of the occurrence of barriers of access to information such as those identified above, some patients, who neither request nor receive explanations, form erroneous conclusions about assumed effects of treatment, or become anxious about their well-being. One participant felt particularly strongly about the lack of information.

"I'd like to know more of side effects. Half the time - you might feel rotten, and it's the drugs. And okay, you can accept feeling rotten if it's the drugs. But if you don't know, you think - what's wrong with me now? And you get more depressed."

A patient who was very anxious about the discolouration of urine expressed anger at not having been warned. Others indicated that they became aware of effects of medication by comparing experiences with other patients, rather than through being informed directly. Several participants explained that they became aware of potential harmful effects on the liver through interacting with fellow patients:

"The rumour was, it plays up with your liver. This only came about by what somebody else had asked."

One third of participants expressed dissatisfaction with the lack of information regarding possible side effects, and the inadequacy of explanations where they were offered. Those who were given clear explanations tended to be those who had experienced more severe side effects. Findings of this study are that patients experienced anxieties that were unresolved, particularly in relation to side effects of drugs. Inferences are consistent with conclusions by Roth (1979) and Tagliacozzo et al (1974) that a positive consequence of interventions to improve compliance is to

legitimise the unburdening of fears and anxieties.

Compliance with the full course of medication not only cures the patient, but protects the community from infection. The finding that only five of the participants were aware of the chemical isolating effects of medication suggests that little use is made of the opportunity to motivate compliance by drawing patients' attention to the need to protect family and community members.

Although most participants were aware that the probable duration of therapy was one to two years, only three were able to explain the reason for a prolonged treatment. It has been established in literature that compliance failure is more likely as treatment is protracted (Fitzgerald, 1976), and if that treatment is believed to be unnecessary (Kellaway et al, 1979), especially in the absence of symptoms as motivators (Becker, 1976). Based on these associations, the potential for compliance of Tb patients to decline is high, as the course of treatment progresses and symptoms recede. In such situations it is particularly important to counteract the possibilities for compliance to fall off by clearly explaining the reason for continued treatment as well as reinforcing the need to comply. One patient attributed her own concern to adhere to treatment to the following experience:

"I remember one lady in hospital - she got better, you know? I think she forgot to take her tablets, thinking she was better, you know? Then she got sick, went back a second time. She told me that. She had to have two operations. She said, 'If I had known, I wouldn't have forgotten to take those pills till the doctor told me to stop.'"

A number of patients were not able to explain the consequences of noncompliance for acquired resistance to drugs. Some, on the other hand, were warned that erratic

compliance could result in resistance to medication, and that alternative combinations of drugs were far less pleasant:

"She said to make sure I did not miss. Because they say that if you miss them for a couple of days, and then go back on them, the body may react against them. It won't do you any good. And the second lot is worse, because it may not work the second time. She emphasised that."

The literature contains conflicting opinions on the use of fear to motivate adherence to a regimen. Marston (1970) points out that minimal fear can encourage compliance, which is supported by comments of some participants in this study that threats of unpleasant alternative treatment constituted a motivator to compliance with present therapy. However, several patients were not satisfied that sufficient emphasis was placed on consequences of compliance failure:

"I think it [the regimen and the need to comply] was explained quite carefully. Whether sufficient emphasis was placed on the alternative - if I didn't, what?...The thought has occurred a number of times since that it wasn't as heavily reinforced as it might have been...I think it is only fear, or fear of a consequence; making you very conscious of it."

A number of participants asked the interviewer about consequences of poor compliance, several of whom expressed concern that they hadn't been given that kind of information. From findings, it can be inferred that patients want to be informed not only of how to take the regimen, but why, and also the likely consequences of not complying.

Dissatisfaction with Information:

Over half of the participants in the study indicated that information about the disease and treatment was inadequate. Of those who were strongly dissatisfied with the lack of information, a typical complaint was:

"I felt all along that there's this terrible lack of imparting information: I found it all through the hospital. It really frightened me, the lack of explanation - just the lack of information, full stop."

Patients criticised the practice of being prescribed medication without being informed about the effects of the drugs. Said one:

"I don't know what any of the tablets do, to be honest. They just told me to take them, and not to miss them. That's all. At the time, I didn't worry. But afterwards I thought, well, a man should have known what they were for, and what they did."

A few patients expressed a contrary view, and were satisfied that information was limited to instructions as to how to take the regimen, making such comments as:

"I don't really care what the tablets do. That's the job of the doctors."

The expressed need by a third of participants for more information and fuller explanations about the treatment is in line with the view expressed by Stimson (1974) that the patient is more appropriately seen as an active participant in the treatment plan rather than as submissively yielding to the regimen. The frustration some patients experienced is expressed in the following comment:

"You have to fish for information. To me, they seem to think the patient shouldn't know...you pick these things up incidentally - you never get it spelled out to you - you just sort of pick up bits and pieces, a comment dropped, and you say - Oh! So that's it!"

Such expressions of dissatisfaction support Brody's (1980) assertion that the capacity of persons for autonomous, responsible behaviour is denied by withholding information. Furthermore, depriving patients of information they may need to make decisions in a responsible way, including compliance with treatment plans, is to treat them as nonpersons. Findings of the present study that most patients were concerned about their lack of understanding of the disease and treatment, and wanted to be better informed, suggest a re-examination of assumptions that patients cannot understand medical matters and would become unduly anxious if given such information. Evidence supports a contrary conclusion, that anxiety is related to information needed, but perceived as being withheld.

Perceived Concern with Compliance After Discharge:

Inquiry into medication in hand: Contact between practitioners and patients occurred mainly in the context of the hospital chest clinic. Most participants reported that they were routinely asked about the approximate amount of medication they had still in hand, and the patient's answer is recorded in the clinical notes. However, practitioners seldom verified the patients' statements, e.g. by requesting patients to bring the bottles of tablets with them and by checking remaining medications themselves. Practitioners who were consulted indicated that to do so would be inappropriate in a situation where patients are explicitly given responsibility for taking their medications from the time treatment is commenced. In addition, as private pharmacists fill prescriptions, the practitioners have no knowledge of the precise number of tablets dispensed as a baseline from which to measure compliance. Therefore, patients are not requested to bring remaining medications with them to clinic, but nevertheless a few reported doing so, in order to satisfactorily answer the physician. One

participant explained that he did so in order to verify his claims that he was taking his medication, which he felt was being queried by his physician.

After the first clinic visit, when the practitioner's interest in the quantity of remaining tablets was experienced, participants said that they would check how much remained before going to the clinic. They indicated that they did not precisely count the number of tablets remaining, but would estimate it, as the following comment suggests:

"He asks you how many are left - he always does that. So - I just look, you know? And say - maybe about a week, you know? He should know or not from what he's written down before, you know? Because if I've nearly finished now, have 20 tablets, he should know whether that is right. Because he knows how many he wrote down."

What the patient did not take into consideration is the cumulative effect of left-over tablets, and that it was likely that he would not have filled and commenced taking the tablets on the day the prescription was written. Therefore, the patient's reply can at best give only an indication of whether or not he is adhering to the regimen.

It is possible that inadvertently the practitioner may be misled by patients' replies, as for instance in the case of a participant in whose clinical notes it was recorded that he had "about two weeks' supply in hand." When the researcher interviewed that patient some three weeks later, he had not yet filled the most recently written prescription, and still had a repeat on the tablets in hand to collect - a factor he had omitted to explain when answering the physician's enquiry about remaining medication. It was recorded in the clinical notes of that participant that he had been

without medication for several days on two occasions, one of them being when he had failed to keep a clinic appointment. From the large amount of medication remaining at the time of the interviews it is inferred to be likely that his compliance was erratic (although he asserted full compliance). A reply to physicians' questions about medication in hand without an objective verification of the position can give practitioners a false sense of security about the compliance of their patients. On the other hand, failure of practitioners to emphasise the need for an accurate response, or to take more initiative in checking out self-reported compliance can indirectly communicate that it isn't a critical issue. Yet from the practitioner's point of view, the use of pill counts to cross-check patient self-report is not feasible for reasons outlined below.

The following factors became evident in the present study, and are also recognised in the experience of practitioners:

- (a) it is not possible to ensure that prescriptions are filled (one participant who still had tablets in hand had not filled a prescription that had been written five weeks previously).
- (b) patients can change chemists for reasons of their convenience (which at least one participant had done) making it difficult for a concerned pharmacist to ensure a person is continuing their treatment.
- (c) there may be several months between chest clinic appointments, and a prescription is written to cover this whole period. The resulting large number of tablets involved precludes a researcher or practitioner counting the remainder accurately enough to measure compliance.

Indirect inquiry into patient compliance: Rarely were patients questioned directly about compliance. The principal means by which compliance was assessed appeared

to be by inquiry into the amount of medication remaining. Many participants perceived this as the physician's way of checking on adherence to the regimen, as indicated by the following assertion.

"He never asks if I am taking the medication. He always asks me how much I've got left. And that's how he works it out."

The perceptive dialogue below suggests that some participants are aware of practitioners' difficulties in assessing compliance.

"It must be, to a doctor like that - it's a big responsibility. He's got to make sure [the patient] is taking them."

"Perhaps to a certain extent they can suss out in their own mind who is likely to carry on and who not."

"Still, how can they tell? How can they tell? How would they...you know, you can only, honestly, trust them. And if they don't, they are only foolish to themselves."

Notations in the clinical notes of several participants indicated potential problems with compliance. From these a range of indicators could be identified, including real limitations in communicating in English, missed appointments, and documented treatment failure with a previous episode of Tb attributed to noncompliance. The participants so identified did not indicate in their conversation that the physicians' approach to them differed in any way from that reported by other participants. Nor at each follow-up clinic consultation was there any direct enquiry into their compliance.

A few participants did, however, report that they had been asked specifically whether they were taking the medication as prescribed. Yet on some occasions even when the issue was raised it seemed that from the way

questions were asked, little real concern was communicated about the importance of compliance. One participant observed:

"I think on each occasion I was asked if I was keeping up with my treatment. But he seemed more concerned about the x-rays. I don't want to sound critical, but I think the questions asked are so routine that they don't even listen to the answers...They are asked so automatically that the questioner is not even listening for an answer."

Others who were specifically questioned about their medication-taking believed that they were suspected of irregular compliance; as suggested by a participant who was asking about the necessity for continued treatment.

"Perhaps he thought - she's been playing with them. But - it's not as if I'm taking them erratically. Because he asked - 'Do you take them every day? What do you take every day? How many of these? How many of those?' It was like a trick questionnaire thing."

When poor compliance was suspected, the patient was questioned more specifically, and the need to comply with the prescribed regimen was generally reinforced by the practitioner in the chest clinic.

One participant currently taking a course of antituberculosis therapy for the third time reported on the physician's questioning:

"He asked, 'Did I take my medicines properly?' And I said yes. Though... the hospital cut my treatment out early, because...I think I was doing good. I don't know the reason...And he said, 'Did I miss at any time?' And I said no. Of course, I wouldn't do that. And he said was I sure. I said - if I have missed any treatment it would be the months that you cut me out of it...Everybody just looked at me. And he didn't like it."

It is suggested that although these more pointed enquiries into compliance were not misplaced, the style of questioning tended to put patients on the defensive, and did not encourage open discussion about the behaviour.

Nursing practice in encouraging compliance: Patients returning to the chest clinic have no contact with nursing staff apart from having their weight recorded by a nurse. Most participants commented on the length of time they spend waiting to be seen by the physician - "long enough to go to sleep", as one person expressed it. That time is not used by nurses to make inquiries about or discuss compliance with patients, nor to reinforce knowledge necessary for compliance or undertake further patient education. Nurses working in the clinic recognised that waiting time is not utilised and that there is a need for patient education generally, and in relation to enhancing compliance. They indicated, however, that they were unable to meet those needs as they were already fully occupied.

In assessing the potential of educative-counselling nursing practice, consideration needs to be given to findings of research. Studies of the effectiveness of nursing educative and counselling interventions in improving patient compliance have had both positive results (Thibaudeau et al, 1977) and inconclusive outcomes (Spector et al, 1979). However, experiences of such studies have shown that regardless of the consequences for compliance, nursing interventions have a value in legitimising catharsis, and therefore, as suggested by Tagliacozzo et al (1974), usefulness needs to be evaluated in broader terms than patient behaviour.

Contact of nurses with patients in their homes for the purposes of assessing and encouraging compliance occurs less frequently than in the past, due to the policy changes outlined in Chapter Five (p.78).

According to nurses consulted, the trend is for public health nurses to visit selected patients only, and not every patient currently taking medication, as previously. However, the basis for selection was not clear in the present study.

Less than a third of participants were visited at home by a nurse. For some, the purpose of the visit was not made explicit, as indicated by a comment such as "She called in because she was making her rounds." In other instances, patients reported that the nurse made enquiries about their management of the regimen. Indications are that greater than usual risks of compliance failure, e.g. with past documentation and/or present suspicion of erratic compliance, and the presence of a resistant strain of the bacillus, do not of themselves constitute criteria to ensure regular supervisory visits. For example, of three patients taking second-line medication, one was regularly visited, but the other two were not seen at all. One household where there were two or more Tb patients received regular visits, whereas in another similar situation no visits were made.

There is evidence in literature that the more support and supervision that can be provided for patients, the higher the rate of compliance (Becker, 1979). Haynes (1979a) suggests further that services to help patients adhere to the regimen are as essential as diagnosing and prescribing. Therefore, confirmation in this study of a trend toward less rather than more home supervision, thereby reducing one avenue by which practitioners can take action in enhancing compliance, is disturbing. This is particularly so in view of assertions by Addington (1979b) and Sbabaro (1980) that poor compliance remains the major obstacle to achieving control of tuberculosis as a public health problem.

Concluding the above account, it is suggested that

there is a need to re-examine the jobs and priorities of nursing personnel working in clinics. With infrequent clinic appointments being the only contact many patients now have with practitioners, the need to maximise those occasions with a view to evaluating and assisting compliance, as Conway-Rutkowski (1982) points out, is a matter of priority.

CONCERN WITH COMPLIANCE WITH OTHER RECOMMENDATIONS

A similar pattern to that presented above emerges when considering the explicit interest of practitioners into patient compliance with lifestyle modifications,

Proscriptive Recommendations:

While recommendations to limit alcohol and cigarette consumption are presented in the pamphlet 'The Treatment of Tuberculosis' (see Appendix 2), individual patients are not consistently so advised. According to participants' comments (p.82), the need to comply with the medication regimen as prescribed is stressed, but the inadvisability of drinking alcohol while taking medication and of continuing to smoke when there is active disease of the lung, is communicated inconsistently:

"I have been a smoker all my life. When I asked the doctor directly about smoking he said, 'It isn't a desirable pastime, but it doesn't seem to have harmed you.' It was not recommended that I stop...It came as some surprise to have the green light - you see, it was emphasised that one must never miss taking the medications. But anything else was not mentioned - even de-emphasised."

Patients who are assessed by practitioners as not having a problem with alcohol or tobacco may be given no information or recommendations about the risks of doing so.

"They don't tell me these things, because they already know I don't drink beer, and I don't smoke."

Information may also be given in a style that leads patients to conclude that it is unimportant. One patient, who claimed that he had reduced his cigarette smoking from three to one packet per day, and "didn't drink much" (in that he drank only beer, two or three times weekly) explained:

"They told us to try and stop smoking, but they always tell you, the nurses and that...Nothing was told me about drinking. But I was asking one of the doctors, and he was saying that so long as you don't drink too heavy? He says there's nothing wrong with it. That's what he says."

Some participants claimed that they took the initiative in asking about the advisability of such practices, because of a felt need for information on which decisions could be made, or because they were seeking validation of information acquired informally (usually from a fellow-patient). In the case of one patient, he believed his inquiry caused the physician to suspect him of having a drinking problem:

"My liver was a bit upset. And I think he [the doctor] got the idea I might be drinking. Because I asked him, two or three times. It was the nurse, she told me not to drink, see? 'It's not good for your liver, not while you're on tablets.'"

Another reported the following reply when inquiring about alcohol, after he became aware of potential effects on the liver:

"...this only came about by what somebody else had asked - because these pills are hard on the liver, apparently. And you don't want to - alcohol is hard on the liver, and you are doubling up - over-taxing your liver, you see? But I was never told anything. I asked - before I came out I asked one of the [doctors] - I said 'Now what's the story on drinking? When I go would it be alright to have a

few drinks?' And he said 'Oh yes, I don't see any reason why you can't.' Those were his exact words."

Presumably that man was considered not to have a drinking problem. Patients who are known to have a high alcohol intake, and particularly if liver function tests are abnormal at the time when treatment was established, are specifically warned that both Tb drugs and alcohol have toxic effects on the liver. One such patient commented:

"I'm not supposed to drink for the rest of my life...I had a bit of a liver problem...a mild cirrhosis...I am also off the drink, because with the medication you can become toxic... Because I take a fair amount of drugs."

Delegation of responsibility to assist compliance:

Within the study group, only three persons were strongly recommended to markedly reduce or abstain from alcohol consumption, and in each case, the responsibility for persuading and supporting the person to do so was delegated to an outside agency. Workers of that organisation would make regular visits to the ward and all inpatients would be encouraged to attend the meetings they conducted about the risks of continued alcohol use:

"We had a meeting one morning down in the dining room - everyone had to go down. This lady came from outside [the hospital], and she talked a lot about not drinking. [Had the practitioners on the ward talked about the inadvisability of drinking?] No. Only that the medicine and drink don't go together. That's all. But this lady - they probably gave it over to her, and she explained more."

The "giving over" of responsibility described by the participant can imply either a relative lack of concern on the part of the one who delegates, expressed in an

unwillingness to remain involved in encouraging compliance to the recommendation, or a lack of expertise in assisting compliance. At the time of the study, none of the participants who had been referred to an outside agency for help with their drinking problem had followed through with advice to attend group meetings. All claimed that they had greatly reduced alcohol intake. The only one who had been instructed by the physicians to abstain from rather than reduce alcohol intake, had bargained with the person to whom responsibility was delegated that he would limit, but not eliminate, alcohol. Physicians' assessments of whether or not a patient has a drinking problem can be inaccurate because they underestimate or are misled about the quantity a person drinks. On the other hand, the following comment suggests that patients can be mistakenly identified as needing extra assistance to reduce drinking:

"When I was in the hospital, this person came round, and said, 'I'd like to see you.' And I said alright. And we went into another room. And she said, 'I hear you drink.' And I said, 'No-o. I don't drink - I do if I go to a wedding, I have one or two. Otherwise I don't drink.' And she said, 'I think I was told the wrong person.' "

The risk of inaccurate assessment could be minimised if ward practitioners took more initiative in actively discussing the issue with patients and educating them about the inadvisability of certain lifestyle practices.

A similar process appeared in relation to a person who was over-weight and taking oral medications for diabetes mellitus. At her first visit after discharge, by which time she had made a considerable weight gain, she was warned in very strong terms of the attendant risks and the need to lose weight. Responsibility for doing so was expressly that of the patient, and she was instructed to rely on an external

agency for assistance to do so. In this way, the practitioner delegated responsibility for supporting her in complying.

Inconsistencies between practitioners: Participants alluded to some inconsistency in the recommendations made by nursing and medical practitioners, as has been indicated above (p.135).

"You see, this sister, she told me not to drink, see? And I asked the doctor two or three times, and he's never answered me. Because she said - 'The doctor will say probably that you can have a drink. But you take my advice, and don't drink while you're on the tablets.'"

Several commented that practitioners did not always follow their own advice, making statements such as:

"All the nurses, of course, were against smoking, on principle. But they all smoked - that's the peculiar part about it..."

Recommendations to modify lifestyle are further de-emphasised in that (according to participants' reports), at follow-up appointments practitioners seldom inquired into or reinforced the advisability of limiting alcohol and tobacco consumption. Only one participant who had quit smoking on medical advice stated that the physician commented on it at each clinic visit, and that was in the form of a statement that the patient had done so, rather than an inquiry into continued abstention, or how he was managing. Other patients indicated that no subsequent comment or recommendation was made at clinic visits. The researcher's impressions gained from participants were verified by practitioners. According to practitioners' statements, compliance with medication is sufficient to cure the individual and, by treating infected persons, control of the disease can be achieved. Current thinking is that

to minimise the number and extent of recommendations made, particularly those seen as more restrictive of a person's lifestyle, would increase the likelihood of adherence to medication regimens. It is probable that recommendations about lifestyle practices are relatively, and in real terms, de-emphasised. At the same time, with the delegation of responsibility to outside organisations, responsibility of practitioners to advise, motivate, and assist patients to comply can be perceived as being shelved. The patient is therefore accountable to the person to whom responsibility was delegated, rather than directly to practitioners, which can be used as a way out of his obligations.

Recommended Measures to Protect Others:

The inference that practitioners communicate nonverbally the relative unimportance of practices other than taking medication, is further strengthened by exploring with participants' recommendations made to minimise the risk of spread of infection. That these recommendations are given with less emphasis than the need for compliance with medications, and probably less frequently, is implied from participants' accounts already discussed in Chapter Five (see Table 2, p. 83). Furthermore, as the following comments indicate, recommended measures may not be explained clearly enough to motivate or enable cooperation:

"The nurse say, 'Let him spit in the bottle.' But he don't know what this is for."

A number of participants made unsolicited comments about non-compliance of fellow-patients with restrictions associated with hospitalisation, such as entering the canteen. Suggested one person:

"It leads automatically to the conclusion that they have not been made aware of what they are doing."

Others clearly understood the nature and reasons for precautions:

"It is spread - through coughing? And through speaking to people. And through me coughing all the time. And that's the quickest way to spread this Tb disease to people...And, of course, that's the reason they give you paper hankies, you know? That when we cough we must cough into paper hankies, and not just cough into peoples' faces. And we are not to kiss people. Like our visitors, when they come in, we aren't even allowed to kiss them..."

It is apparent from participants' comments that while some patients are clearly advised as to what precautions are necessary, others have no recollection of recommended measures. This is attributable, according to a practitioner consulted, to possibly omitting to advise some patients, or that the message wasn't understood.

Compliance of practitioners with recommended measures:

As noted previously in relation to smoking (p.138) consistency between practitioner behaviour and recommendations is one of the nonverbal cues which patients use in attributing importance to recommendations. Similarly, the consistency with which practitioners applied "ward rules" was noted. Apparent poor compliance of practitioners with certain regulations, and recommendations for health, could constitute a role model for patients. Six participants specifically commented on this when discussing measures necessary to prevent spread. One was describing the restriction on patients going to the canteen, but added:

"After tea there was another nurse, a young one, and she didn't used to mind. So we would go then."

Three were permitted into the kitchen, an area out of bounds for patients, and one of the few restrictions enforced by senior nursing staff. Said one participant:

"You know, patients aren't allowed to go into the kitchen, but you are allowed to go in and make everyone's toast at night, and cough all over it!"

Patients were also aware that staff were not permitted to accept patients' food, but one explained that she persuaded some of them to take food brought in by her family.

The healthy population is protected from tuberculosis not only by adequate treatment of infected persons and by their conformity with measures to protect others, but also by follow-up of contacts. The first two modes of behaviour depend on compliance of patients, but with the third the responsibility lies with the Health Department, and is implemented by the nursing service. It involves identifying and investigating contacts, treating those already infected, and protecting those at risk with B.C.G. immunisation (Benenson, 1975). All participants reported that they cooperated with identifying contacts. One person who was extremely anxious lest the fact that he had Tb became known, agreed only after assurances that he would not be named or identified in any way.

Delays in investigating and immunising contacts caused some concern, as indicated by the following account:

"The nurses came, and did the first Heaf. They said they would be back in six weeks to do the other. The six weeks went by, and I was wondering if I should ring them. Then eight weeks went by before she rang."

Three participants who had been informed that their children were to be given a B.C.G. expressed concern that this had not yet been given to some at six, seven, and nine months after the diagnosis was confirmed, and were anxious about the susceptibility of their children.

Two contacts who were given a choice as to whether or not to submit to chest x-ray were uncertain as to whether they had made the correct decision, particularly one who had not had an x-ray and had subsequently lost weight and was having night sweats.

If patients perceive the approach of the provider to be lax in the matter of follow-up of contacts, they may infer that the public risk of infection from Tb is not great. Potentially this could influence patients' attitudes to recommendations, and the importance of compliance with them. Furthermore, perceived poor compliance of practitioners with certain ward regulations and with follow-up of contacts could provide justification for failure of the patient to comply with recommendations. These findings support a suggestion by Gordis (1979) that attention needs to be given to the behaviour of health care providers as well as to patient compliance.

CONCERN WITH COMPLIANCE WITH CLINIC APPOINTMENTS

The provider is seen to be explicitly concerned that patients conform with scheduled chest clinic appointments, and to have the power and means of retrieving nonattenders. This latter point is in contrast with what is perceived as limited direct concern about patient compliance with the medication regimen, proscriptive recommendations, and measures to protect the public.

System to Facilitate Clinic Attendance: Chest Clinic staff described the following procedure (referred to in Chapter Five) to the researcher. Soon after the patient has attended the clinic, details of the next appointment made are mailed to the patient at the time it was made, and a week or two before the due date, a duplicate is sent as a reminder. The practice shows similarities to the system of encouraging compliance with clinic appointments described by Lowther et al (1982). Most

participants viewed the system favourably as indicated by the following comment:

"There is a written notice just before the appointment, which as far as I'm concerned is excellent. Being aware of the ease with which one can overlook an engagement one is anxious to keep, a party for instance, it would be very easy to overlook a hospital appointment."

Even then, patients can forget an appointment, in which case, if the patient doesn't communicate shortly, a rescheduled appointment is sent. That procedure effectively resulted in the eventual attendance of four participants.

From personal conversation with practitioners, it became clear that patients who persistently fail to attend clinic and may also not respond to attempts at retrieval, become well-known as "defaulters" or "recalcitrants". No patients in that category were participants in the study, partly because in the experience of practitioners, "defaulting" is not common while patients are still taking medication.

Factors that may Discourage compliance with appointments were identified by patients. One that was raised by half the participants is the time that must be allowed for the appointment, most of which is spent waiting, as the following comment indicates:

"My appointment was at 1.30. After a while had a chest x-ray. Then, you sit there and wait. And eventually, I got to go in after 3 pm, and that was only because I went and saw the sister and told her I had to collect my daughter from school. You have to allow half a day for it. So, by the time you get in there, all you want to do is to get out as soon as possible."

Others mentioned the distance and cost of travel and difficulty parking, and the need to take time off work. These were not considered major problems, however, as clinic attendance was required only once in two to three months.

It is suggested that failure to comply with clinic appointments is readily determined by practitioners, is more easily amenable to strategies to facilitate compliance, and nonattenders can usually be located and persuaded to attend. Practitioners can therefore function with greater confidence in their assessment and means available to enhance compliance with clinic appointments.

Confidence in oneself and organisation to ensure compliance can be communicated nonverbally to patients, and motivate conformity to appointments. At the same time, an occasional presentation at clinic requires less behaviour change of the patient than compliance to prescriptions and other recommendations. The interaction of these factors gives rise to a higher rate of compliance even in the presence of difficulties, such as time expended and distance and cost of travel.

SUMMARY AND CONCLUSIONS

The way practitioners educate and assist patients to comply with a protracted and obligatory course of treatment has been the focus of this chapter. As is consistent with the research design, the patient's perspective on activities of practitioners has been taken. There is a positive relationship between perceived interest of practitioners in compliance to the specific recommendations, and the availability of means to assess and encourage compliance. For example, compliance with clinic appointments, which is readily monitored with means of retrieving noncompliers, is actively encouraged by the appointment system in use and other organisational practices. On the other hand, adherence to the medication regimen and cooperation with lifestyle behaviours, are less straightforward to assess, with active involvement of practitioners in inquiring into and encouraging compliance being perceived by patients as correspondingly lower. It is argued that practitioners are communicating by subtle and nonverbal means their relative ability to enhance or enforce compliance. At the same time, it would seem that their level of concern actually varies with the different recommendations.

From the content of patient education, practitioners seem chiefly concerned with compliance with medication. However, education of the patient about the treatment is seen to be limited to providing instructions as to how to follow the regimen accompanied by verbally reinforcing the importance of complying with those instructions. Many participants were dissatisfied with not being informed of the action of drugs and rationale for treatment. Whereas practitioners explained that information was limited so as to avoid unnecessarily alarming patients, the patients themselves indicated that anxiety arose from a perceived withholding of information. This supports Brody's (1980) capacity theory, which suggests that not providing patients with information about their illness and treatment is not only to treat them as nonpersons, but denies their capacity to function as autonomous, intelligent persons.

It is apparent from participants' accounts that patient education does not meet the felt needs of patients. Furthermore, the adequacy of patient education in preparing people to continue following the regimen is questioned in the light of findings presented in Chapters Five and Six. A need is indicated to relate health care practice concerned with compliance to the needs of ambulatory patients as empirically assessed. In his description of status passages, by which a change from one discreet identity to the next is marked, van Gennep (1963) suggests that practices are necessary to ease the transition and to minimise harmful effects of the change. Medical and nursing practice to enable compliance can usefully be seen in relation to the concept of status passage. The evidence discussed in this chapter suggests that current practices need to be evaluated, so that the transition to status of ambulatory patient responsible for and competent in continuing the course of treatment, is facilitated.

CHAPTER EIGHT

THE ILLNESS EXPERIENCE AS A FACTOR IN COMPLIANCE

While they were describing ways in which they managed their regimens in the domestic environment, participants tended to become emotional over two issues. One of these, already discussed in the previous chapter, concerns dissatisfaction with information given them to enable compliance. Some indicated an unhappiness at not being treated as responsible persons with an interest in their own treatment and recovery. The other issue relates to the illness experience itself. Many participants discoursed at length about such concerns as how and why they became ill, and how recovery could be promoted. Acknowledgement of other issues raised by patients allows compliance with the therapeutic regimen to be viewed in relation to the person's whole life situation. That is to say, the phenomenon of compliance is seen in context as one aspect of the total illness experience with its associated concern for recovery of health.

Participants' perceptions of the seriousness and threat of having tuberculosis along with symbolic meanings associated with having an infectious disease are discussed. It becomes apparent that subjective experiences of having Tb do not always reflect the changes in management and treatment options that have taken place in recent times. Consequently, the perspectives of practitioners and patients on tuberculosis may not coincide. The result is that patients who believe the disease to be serious and difficult to cure may be receiving treatment from practitioners who regard it as readily treatable and straightforward to manage.

SUBJECTIVE EXPERIENCES OF HAVING TUBERCULOSIS

The dread that was at one time associated with tuberculosis is indicated by the name commonly used in the prechemotherapeutic era, "consumption", with its overtones of being eaten away by disease.

Fear of being afflicted threatened all sectors of society, including the well-off, and was prevalent through adolescence into young adulthood. Romanticising the consumptive way of death, suggests Dubos (1982), became a way of coping with a disease of unpredictable outcome for which there was no known cure, and from which such famous personages as Keats, Chopin, and Katherine Mansfield died. With the availability of a range of effective antituberculosis agents, Tb is now regarded as a curable disease provided the patient complies with the full course of treatment as prescribed. Evidence has been presented in Chapters Five and Seven (pp.82, 134) that from the perspective of patients, the practitioners' concern with the medication regimen and patient compliance emerges as dominant. Participants indicated further that there was little discussion of the emotional impact of being ill, and diagnosed as having tuberculosis, although these are important issues to patients, and their families.

Impact of the Patient's Illness on the Family:

In common with other illnesses during which a period of hospitalisation and inactivity is necessary, patients' families are affected by the event. For example, separation from children and restriction on children's visiting throughout hospitalisation was noted by a number of patients to cause particular anxiety to families. During the hospitalisation period, families needed to organise themselves to cover child care and other domestic responsibilities, particularly if it was the mother who was ill. Patients had their private anxieties about their families, such as how they were coping, and concerns for safety when travelling in daily to visit. Many families were under financial strain as a direct consequence of the illness. Families of wage-earners with little or no savings experienced hardship when the wage was abruptly suspended and the sickness benefit was insufficient to cover customary living expenses. Several families in the study were supplied with food coupons by a voluntary welfare organisation, to tide them over the crisis period, and the families of two were assisted through collections of food and money by people from their churches or workplaces. Four

participants left work or were asked to resign because of the severity or duration of the illness, and two others were given lighter duties after resuming work.

It is evident that social and economic effects of the illness can be considerable. Drake (1973) asserts that total patient care by practitioners includes assisting the family to cope with such crises. Further, the subjective definitions of severity, should indicate appropriate interventions. Although in several instances the illness seriously disrupted family functioning, indications are that voluntary organisations and social services provided support, with health care practitioners being concerned chiefly with medical treatment. Prevailing opinion that Tb is no longer the serious disease it used to be may account for the infrequency with which practitioners expressed concern about social effects of the illness, as reported by patients.

Perceived Seriousness of Tb:

On being informed of the diagnosis of Tb, patients reported a variety of reactions. A small number of participants who feared they may have cancer indicated their relief when the diagnosis of Tb was made. Others experienced a negative response, as indicated by one person who reported that, after a series of investigations had been carried out:

"...a doctor came along and said 'I'll give you the good news first.' And I said 'What's that?' And she said 'You've got Tb.' Well, to me Tb was like a death knell, at that stage."

For a practitioner to state that having Tb is "good news" implies that recovery is a foregone conclusion. However, the experience of the small number of Tb patients who comprised the study group suggests that this isn't invariably so, as has been documented in Chapter Four (p.68). For instance, four of the 22 participants had had courses of Tb treatment on two and three occasions in the past. Eight participants had close

relatives who had had Tb, and a few described the decline and death of a family member from Tb in the prechemo-therapeutic era. All of these factors have an effect on how patients perceive the threat of Tb to themselves today, which as Herzlich (1973) indicates, is perceived as serious although generally regarded as curable.

A patient's initial reaction can change along with his experience with the illness and treatment. Commonly, as the person begins to feel better after a few weeks of treatment, the initial shock is replaced by a confidence in the outcome of therapy. On the other hand, a number of patients who responded only slowly to treatment or developed complications, underwent changes in their beliefs in a reverse direction. On being first informed of the diagnosis, one reported response was:

"Thank goodness for that! But now - I'm not so sure. Then, I thought that if you have cancer you would die. And yet they say in the olden days people used to die of Tb. Well, they sort of let me out [of hospital] thinking I was over it, but it has come back and back - and they are still pumping these pills into me!"

A related factor is the perceived threat of symptoms of pulmonary Tb. Participants whose disease was discovered through mass screening, follow-up of contacts, or in the course of investigations for another problem, experienced very mild or no symptoms. Those persons, together with a number who experienced only mild fever and night sweats, and a cough, did not perceive Tb as either serious or threatening to life, as suggested by the following comment:

"What I feel is nothing to do with Tb. Tb don't worry me. Won't do any harm. But it's the blood pressure, you see."

Almost half the participants experienced chest pain, and three had coughed up blood on at least one occasion, as one man explained:

"One day I was washing the dishes or something, and I started to cough, and it came out blood...I thought I was going to die. I went outside, and coughed and coughed, and then started for the doctor. How much? - about a mug I suppose. Ugh! They reckon it was the Tb that's inside of me, and gnawed away at me all the time."

Patients who experienced such symptoms tended to perceive Tb as serious and threatening. This is consistent with suggestions by Wu (1973) that the threat an illness is to one's life is closely related to the organ affected, and the effect on processes essential to life. Thus, the experience of chest pain, particularly when it seems to interfere with breathing, and the loss of blood - symbolically associated with life - cause great anxiety.

Relationship of beliefs and compliance: A characteristic of the medical model is that the diagnostic label does itself indicate the appropriate treatment and suggest the prognosis, with a result that all patients with the same disease are managed in a similar way. Findings of this study suggest, however, that there are considerable individual differences in the subjective experience of symptoms and in the way the disease is perceived. The way that subjectively disparate beliefs about a single disease can affect compliance behaviour is suggested by the Health Belief Model (Becker, 1976). Perceptions of the severity and threat of the disease, and of the believed efficacy of treatment to reduce or eliminate that threat, are identified as variables to explain and predict compliance.

Indications in the present study are that perceived threat from symptoms or illness did motivate continued compliance even after symptoms had abated. For instance, the person who had coughed blood went on to explain that no further episodes of bleeding had

occurred since he began taking medication. He inferred that as he believed that medication prevented further bleeding, he was highly motivated to adhere to the regimen. Others explained that they took care to follow the regimen so as to prevent relapse, as suggested by the following:

"I was sick, so ill - waste and waste, weak and weak, every day... Now? Oh boy, eat well! Sleep well - not tired. And I'm happy. I really think the sickness gone - but I still am taking the tablet. Every day, never miss, that's why."

While there appears to be a positive relationship between perceived threat, and compliance in order to eliminate threat, the converse relationship did not hold. On the other hand, according to participants' reports, no relationship emerged between compliance failure and the nonoccurrence of threatening symptoms and/or a belief that Tb is not serious. In the absence of these naturally occurring motivators to compliance, there are indications that practitioners can compensate by directly encouraging compliance. A patient who was asymptomatic explained:

"I don't know how long I'm on these for. The doctor knows what I need - it is for my own good, so I'll do as he says."

It can be inferred that a trust in the practitioner's judgement is likely to result in patients taking seriously recommendations that are emphasised and repeated, namely, to adhere to the prescribed medication regimen. Therefore, in situations where beliefs about symptoms or the disease do not in themselves motivate compliance, practitioners can develop positive attributes of the practitioner-patient relationship to promote compliance. A necessary basis for doing so is to correctly identify the perceived threat the illness constitutes for the individual patient. The H.B.M. developed by Becker (1976)

lends itself for this purpose. A person-centred approach to encouraging compliance in the context of holistic patient care, as advocated by Paulen (1981) is therefore appropriate.

Stigma Associated with Tb:

Although the efficacy and style of treatment of Tb has changed dramatically over the past few decades, yet the fear and associations of the prechemotherapeutic era linger.

Wu (1973) has noted that certain diagnostic labels can carry meanings associated with a tradition of common experience. Specifically, Tb is associated with fears about status and family relationships, a position expressed by a participant as follows:

"I can remember it being one of those diseases that are spoken of in hushed whispers. If someone in the family had it, well, that was it - and they became outcasts."

One patient literally spoke in "hushed whispers", dropping her voice to a whisper at least ten times during the dialogue when she mentioned "tuberculosis" by name. To another, people who got Tb were "pale and insipid" (he described himself as an active man), and he and his peers used to look on Tb as a "bad thing". The majority of participants made some references to difficulties experienced in integrating the label of Tb into their self-concept, which suggests an incongruence between stereotyped notions about Tb, and their personal experience of the illness:

"It's very hard to accept the fact that you've got something like tuberculosis, which to me is something really horrible. It's like having V.D. It's just not a sociable disease to have."

Concern about the status of now being a "Tb patient" led to a searching for the cause, a theme to which a number of

participants returned several times during conversation. Several patients referred to factors that they believed increased their susceptibility to Tb, the most frequent being "run down" (mentioned by a third), and occupational risks (involving four). For the most part, as indicated by their comments, patients were bewildered and even angry at the apparent injustice of having Tb:

"There was a considerable amount of research and brainsearching to try and arrive at a conclusion - I mean, for it to appear in a relatively healthy and affluent society, like this, well, it's a bit of a shock. I was actually very puzzled - how the hell did I get it!"

A number of patients described the "typical" Tb patient, identifying such characteristics as deprivation and poverty, alcoholism, neglect, and ethnicity and age group. At the same time, few participants saw themselves as susceptible to tuberculosis, whatever their age, ethnicity, or work and living conditions. Those who fell into a high-risk group, as stereotyped by others or described by themselves, frequently identified criteria which would exclude them:

"I just don't understand how we [Maori] get that sort of sickness, that Tb. I used to think - I'll never get it because it doesn't run in my family. And I used to say - most of the people who had Tb, they were all skinny people. They weren't fat, not like me. Of course now - it's so hard for me to believe that I've got Tb. And I was so shocked."

Thus, most participants indicated difficulties in accepting the label of tuberculosis, and of incorporating the status of being a Tb patient into their identity.

Self-Concept as "infectious": An aspect of the status of Tb patient that people indicated as being difficult to accept was that of being infectious, and of the associated "carrier" status:

"They said when I went into hospital that I was full of it! I was positive direct! Oh, my gosh, oh I was dreadful! They were just oozing out of me, the bugs...Oh, it was awful! It was dreadful! You weren't allowed to go anywhere...you weren't even allowed to go into the canteen. You felt dirty! It was horrible."

Having contracted a communicable disease, patients would then be concerned about who they could have caught it from, and to whom they could have transmitted it. A few participants were particularly concerned with those issues because of a desire to take action to prevent a recurrence, and made suggestions such as raising workplace standards. Several patients expressed relief that follow-up investigations of contacts, mainly with family members, confirmed that they were disease-free, and conversely, in instances when another family member contracted the infection, considerable distress was experienced.

Whether or not patients have difficulty in accepting the diagnosis of Tb, and adjusting to their "carrier" status, may be assumed to be inconsequential to the treatment plan and compliance with prescribed regimens. However, it is likely that these feelings affect their attitudes toward following regimens and recommendations. Furthermore, the concepts people tend to form about their infectious status could be utilised to impress upon them the need for compliance with measures to minimise the risk of spread. At the same time, there is a need for education, so that patients' ideas about communicability of the disease is consistent with current scientific thinking, and that negative effects of undue anxiety and preoccupation with self-concept can be modified.

While the status of being "infectious" focuses on the patient's feelings about himself, stigmatisation refers to a person's perceptions of how others may feel about his status. An extremely anxious reaction was encountered in the course of the study, when a patient became agitated and tense in case a visitor in the house learned of the purpose of the interviewer's visit, and the fact of the disease. He explained:

"You mustn't talk about it. It's so secret. It makes us ashamed. No-one must know - only the hospital, the doctors and nurses. No-one else- not even neighbours. Not even friends, not even relatives must know."

There is a possibility that fear of having one's status revealed could result in a person not cooperating with naming contacts or place of work. In this instance, the patient stated that he cooperated in identifying contacts only after being repeatedly assured that his identity would remain concealed. The wife of another participant described the approach made to her while she was at work, which suggests that the issue is a sensitive one, and the instance cited above is not unique.

"The nurse who came to see me was a real sweetie, and she didn't want anyone to know what she was talking to me about, you know...Because - I don't know how she thought I could react, you see..."

Although reference to a stigmatised identity was made frequently, there was no evidence in this study that patients failed to cooperate with health practitioners for that reason. One participant described graphically her embarrassment at having to present a prescription for Tb medication to the local pharmacist whom she knew well. However, she had made no attempt to conceal the fact of her illness either by going to an unknown pharmacist, or failing to fill the prescription. Only one patient referred to the effects of the medication in discolouring urine as stigmatising, but this did not

reportedly interfere with compliance with taking medication. However, the need for practitioners to assess the extent of stigmatisation experienced by patients is indicated, in order to avoid unnecessarily aggravating the situation. Two asymptomatic patients were reluctant to accept indications of the presence of disease and enter the health care system. Their initial lack of cooperation seemed to stem mainly from the disgrace associated with having Tb, and one in particular remained very critical that in his opinion practitioners did not take more care to respect his fears of being found out.

While fear of stigmatisation seemed not to interfere with compliance of participants, it is suggested that the experience of negative self-concepts as "Tb patient" and therefore as "carrier" may be employed to motivate patients to comply with regimens in order to be rid of the stigma. Furthermore, stigmatisation in a person's experience in itself constitutes a crisis with which the patient may need assistance to resolve.

Stigma management: "Stigma" refers to the spoiling of one's identity, whether there is visible evidence of blemish or not, and stigma management is a process that occurs in society wherever there is deviation from societal norms (Goffman, 1963). There is evidence in the present study that Tb patients felt their identity to be blemished even though stigmata were seldom visible, and the mode of managing the treatment reflects professional opinion that Tb is not a stigmatising disease. Said one:

"We were talking about this in hospital, and one of the chaps said, 'Don't you believe it hasn't got a stigma, because it has.' You see, everytime he tried to get a job, it just wiped that job."

As well as commenting on Tb as "socially unacceptable", and associated with poverty, neglect, or personal weakness, certain patients made references to being "marked for life", "permanently scarred", and "on their files for the rest of my life." Some participants although clearly informed that the prescribed course of therapy would cure the disease still expressed fears that their identity was permanently spoiled.

Many patients described their perceptions or anticipations of how others would react toward them when the fact of the disease became known, in such terms as:

"You could almost sense the standing-back attitude...I know that quite a number of them dashed off at high speed to their doctor to make sure they hadn't got it. Understandably, as they had been in contact with 'that person' for a long time, and may have acquired it."

Most persons who discussed their feelings of being stigmatised could produce comments made or action taken by "normal" people which reinforced their fears of having a spoilt identity, but in no case did they report that people actually withdrew from them or isolated them. One described her relief that people continued to visit her:

"...because I just thinking that it could be no relative or friend come, because it's serious disease I had."

The critical issue in stigma management is the acceptance by normal people of the person with a spoiled identity. There is a difference between being discredited, when the blemish is obvious or well-known, and being discreditable, when the stigma is not visible but there is always a risk of the fact being revealed.

Then, the individual is faced with a dilemma of whether or not to tell, or to work at keeping it concealed (Goffman, 1963). In the experience of one woman:

"It is embarrassing to have this Tb. When people ask me, I don't tell them. I just say - I am a very sick woman. I have to take treatment for one or two years. If they ask me what's wrong, I just say - I'm not the doctor, am I?"

Goffman (1963) suggests that stigmatised people may expect support in identity management from those who are similarly discredited, or from the "wise" - normal people who by reason of occupation or vocation are close to the stigmatised, and able to understand and empathise. There are indications in the present study that in the community, nurses function as "wise" in relation to Tb patients. In the process of following up contacts, the nurse may assist in concealing the identity of a registered patient, as indicated earlier in the chapter.

It can be inferred from the frequency of expression about stigmatisation that it emerges as significant in patients' experiences. Moreover, the identification of the researcher also as a nurse, and therefore as "wise", may have facilitated catharsis in relation to their identity crisis. Although in the study group fear of stigmatisation seemed not to interfere with compliance, it did cause anxiety to several. Anxiety potentially delays recovery, and therefore, at the same time as assisting patients in managing their regimens, a need is indicated to reduce anxiety by assisting patients in the management of a spoiled identity. This is consistent with findings by Tagliacozzo et al (1974) that interventions to enhance compliance should not be evaluated solely in terms of compliance behaviour. Because interventions to improve

compliance may legitimise the unburdening of concerns and anxieties, usefulness should be evaluated in terms of total patient care. Such an approach would be consistent both with inferred professional opinion of Tb as a nonstigmatising, curable disease, and with care of the whole person.

CARING FOR HEALTH

In the prechemotherapy era, the mainstay of Tb treatment were sanatoria, the principle of which was to allow the body's natural healing processes to occur by providing adequate nutrition and rest, and an abundance of fresh air (Burnet et al, 1972). One of the participants in the study had experienced this in his adolescence, and along with a number of others whose relatives or friends had spent time in a sanatorium, was able to describe the style of treatment. With a range of effective drugs now available which cure tuberculosis when taken regularly over a prescribed period, interest has shifted away from caring modalities to an emphasis on the regimen and compliance with it to effect a cure. A number of patients in this study, however, expressed a felt need for information on health care, as distinct from the prescribed regimen to achieve recovery.

General Health Care Measures Advised:

Four participants only stated that they were advised to avoid fatigue and to rest during the day. All four had had a serious and prolonged illness, and two had acquired resistance necessitating surgical treatment. Of these, two reported following advice given. One of those who did not conform to advice gave as her reason a dislike of "being an invalid". The other, who claimed he worked 80-100 hours per week, insisted that advice to avoid fatigue referred exclusively to heavy physical work, and not to long hours or mental stress.

Two persons reported being advised about their nutrition. One, a very thin woman who described her lifestyle as "erratic",

had made no changes in response to advice to have regular meals. The other, an alcoholic, who had neglected nutrition, had made appropriate changes to existing patterns. In addition, two diabetic patients were prescribed diets, one of whom experienced problems in adhering to a restrictive diet. The other, an insulin-dependent diabetic, reported changing his eating patterns as instructed.

Of the few patients who reported being advised on general health care measures, about half claimed they followed recommendations. The experience of a greater sense of well-being through enforced compliance during hospitalisation can motivate perseverance with improved personal health care:

"You come out like - really good. I haven't been like this for donkey's years. It is a marvellous sensation."

Other patients failed to conform because they believed certain measures to be unnecessary, or on the other hand, followed advice because it was congruent with beliefs already held, or habits practised. This lends support to assertions by Stimson (1974) that the pattern of compliance becomes understandable in relation to the person's perspective on the illness and on recommendations made, rather than in reference to instructions given.

In most instances, though, participants reported that they could not recall being advised about health care. While patients were discussing recommendations made to them by practitioners, none mentioned matters relating to general health maintenance. Replies were for the most part negative when the researcher asked specifically if such advice had been given, at which point some participants expressed concern that the issue was ignored:

"No, nothing at all was mentioned. Thinking back, I would assume that one would only have to say 'Look, diet is important. Rest is important.' What is meant by that wouldn't even need to be spelled out. Just so that people would be made aware."

Practitioners who were consulted verified that recommendations on general health care matters were seldom given, and that emphasis is now placed on adherence to the medication regimen. The reason given is that since anti-tuberculosis chemotherapy is now sufficiently potent on its own to achieve cure, other issues can be avoided without jeopardising the patient's chances of recovery. The patient would be more likely to comply with a single prescriptive recommendation than a range of advice. At most, according to patients' comments, those who had no outstanding needs would be advised to "take it easy" or "don't overdo things."

It is possible that if patients take the de-emphasis on caring for health literally, outcomes can be undesirable. For instance, two patients reported returning to work the day of discharge from hospital. Another two returned to working a twelve hour day or more after several months of illness, soon after discharge. Two described the fatigue they experienced when they first returned to work, but they persevered over the next weeks in the belief that the doctor, who assessed them as fit for work, was the "expert" in such matters. An incongruence between a commonsense model and the scientific model of health has been suggested by Mechanic (1972) as a reason for compliance failure, in that the commonsense model is the one that determines use of recommendations. There are indications in the present study that the patient can subsume his commonsense perspective and his intimate knowledge of his body to the scientific model, with the result that his body wisdom fails to guide him in health maintenance. One woman, on whose clinical notes it was recorded that she had "irreversible damage to lungs leaving her with limited reserve of lung function", was finding on resuming work that she was constantly tired. Her husband was

urging her to request the physician for a certificate, but she explained:

"I feel guilty. Might be the doctors think I'm lazy? But truly, I feel tired."

A few participants reported that they did not receive medical validation of their own felt needs for less demanding work hours. One who was aware of the stress of shift work, as well as the disruptive effect it has on routines such as that including the medication regimen, asked the physician to request regular hours meantime. She received no cooperation, the explanation being that there was no reason why she shouldn't be fit for a full work load.

Perspectives and Expectations of Patients:

Patients' accounts such as those above suggest that there is some disagreement between the narrowness of the medical model definitions of causation and treatment, and personal beliefs. One person clearly explained his beliefs about causation, and indicated practices consistent with that belief:

"What I've been taught - told - you get by germs, or you get from someone...But what I think - I think it comes from - I don't really care for myself, you know ...I think it comes from cigarettes, or - cold weather. You know when you get cold, wet and cold. What do you think?"

He went on to explain that he realised his "big mistake" in neglecting his well-being (during a personal crisis), cut out alcohol and tobacco consumption, and took care to protect himself in wet and windy weather. Another who attributed his illness to neglect as well as the micro-organisms modified his lifestyle with the objective of reaching a goal "to see the Year 2000" that he set for himself.

"It all boils down to using my common sense, and look after myself...They didn't really suggest anything. The Tb is put to sleep because of the treatment. And the rest is up to the - because it attacks when you're at your lowest, doesn't it? So, I make sure I don't get to that."

Further indications that patients believe that healthful practices as well as the medication regimen are important are provided in their reports of efforts of their families to elicit information about caring. Family members may go to considerable lengths to acquire information, and even then it can be nonspecific, as one patient explained:

"I came home, and I don't know what I can do, what can I not do, I don't know, nobody tell me. I ask the nurse - they say nothing special, no, nothing. But I find out after I not well. Sometimes I not well - and I don't have to do anything."

Her husband added:

"It is nothing specific; just not well, and nothing in particular precipitates it...Before she came home, I asked - just to be sure. And they told me that she had to be careful and rest, make sure she didn't overdo things, and make sure to take the medication. But virtually - nothing specific. I don't think it's their fault - I don't think they [the nurses] are given any instructions, nothing specific to tell the patients."

Others similarly received nonspecific advice when they took the initiative in seeking out instructions. One described herself as "desperate for information". Assurances that no special care was needed seemed to result in uncertainty and frustration amongst patients' families, rather than reassure them.

From limited data, it appears that the nurse is

identified as the practitioner qualified to provide information about health care, and that the family of the patient tends to take a more active role in soliciting that information. However, according to patients' accounts, nursing as well as medical practitioners indicated that health care measures are generally unimportant. A reliance on the therapeutic regimen to achieve cure and associated redundancy of health care measures is consistent with the medical model, and was inherent in the treatment plan. When the medical model is adopted in the nursing management of Tb patients, it appears that the expectations which some patients hold for nursing personnel to provide specific health care guidelines are not met.

SUMMARY AND CONCLUSIONS

This chapter has focused on issues which patients identified as important subjectively, but which received little attention from practitioners relative to that concerned with treatment plans. Although subjective experiences of the illness were frequently threatening, from patients' accounts these fears were seldom discussed with practitioners. The frequency of reference about stigmatisation and difficulties in incorporating the status of Tb patient into one's identity, suggests that this too is a significant issue in the experience of Tb patients which may not be adequately resolved. Further, there is evidence of a lack of agreement between practitioners and patients on the need for health care measures to complement the therapeutic regimen.

Dissonance between practitioners' and patients' beliefs about patient needs and emphases in management may have consequences for the quality of patient participation in the treatment plan. It is suggested that in the context of assisting patients with the management of their regimen, matters that are important to patients, such as anxieties related to the illness, management of a spoiled identity, and felt needs for information on health maintenance, need to be given attention. In this way, not only will the unburdening of

worries be legitimised, but advantage will be taken of opportunities to recognise and correct erroneous beliefs and notions. The apparent incongruence that sometimes exists between patients' beliefs about treatment and prognosis of Tb, and current treatment options, can thereby be reduced. It is likely that felt needs for information about nutrition and activity in some cases reflect the pattern of treatment in prechemotherapy times. But it may also indicate characteristics of patients' commonsense models for health, which are necessarily an integral part in person-centred care. Furthermore, a failure of practitioners to acknowledge needs expressed by patients can result in patients deferring to "expert" opinion and ignoring subjective body wisdom which usually guides them. The illness event, nevertheless, provides an opportunity that practitioners, particularly nurses, could utilise to educate patients with a view to influencing self-care practices in the direction of improving health in the long term.

By using a person-centred approach, issues and experiences that concern the patient would be recognised and dealt with in the context of assisting the patient to adhere to the regimen. When the patient is given opportunity to express his fears and concerns, there may be a greater readiness to respond to recommendations made by the practitioner. In this way, as suggested by Barofsky et al (1979) patient compliance can be enhanced indirectly, as a response by the patient to having his disease treated, while being cared for as a whole person with a real interest in his treatment and well-being.

CHAPTER NINE

CONCLUSIONS AND IMPLICATIONS OF THE STUDY

The evidence from this study of patient compliance in which a phenomenological approach was used challenges some of the prevailing practices whereby persuasion and policing are seen to be the most appropriate means of achieving a high level of compliance. It is suggested that a more positive view of the person in relation to intent and ability to comply better represents the patient undergoing treatment for tuberculosis on an ambulatory basis.

An interpretation of patients' perspectives suggests further that compliance with a prescribed course of treatment needs to be seen in relation to broader contexts of on-going health care. Looking at compliance in the context of the patient career, the hospitalisation stage is clearly a critical period for preparing and assisting patients to manage regimens over prolonged periods. These conclusions have several implications for health care practitioners, in particular that practices during this period need to facilitate the transition of the patient to the status of ambulatory patient. The chapter concludes with recommendations for practice and suggestions for further research that have arisen out of the study.

A SUMMARY OF PATIENTS' PERSPECTIVES ON COMPLIANCE

As a lead in to drawing out the implications of the study and making recommendations for practice, the findings reported in Chapters Five - Eight are reviewed briefly below.

Chapter Five reported the outcome of exploring patients' subjective experiences in relation to compliance, as a result of which compliance came to be seen as more than a static response to medical orders. It was apparent that compliance with prescribed medication

differed qualitatively from that with recommended lifestyle changes. Furthermore, family and other social factors in the patients' domestic environments affect the ability of patients to continue to comply with such recommendations.

Chapter Six elaborated on these individual and social factors, showing compliance with the medication regimen to be an active process whereby patients developed their own ways and strategies of ensuring compliance. It was also evident that patients' families had an influence on patient compliance, both negatively, as when little interest was shown, and positively, to the extent of managing the regimen for the patient. These findings indicate that patients are themselves interested in following through with the course of treatment, and especially when supported by their families, will initiate ways to assist them in doing this.

Patients' perceptions of the ways practitioners prepare and assist them to manage regimens were described in Chapter Seven. The scope of patient education conformed to a view of the patient as obediently following the treatment plan in a situation where no contingency decision-making would be required. What in fact happens in the experiences of ambulatory patients, as documented in the present study, raises questions about the adequacy of current practices to assist patients with compliance.

Finally, in Chapter Eight, where compliance is considered in relation to the experiences of being ill, it became evident that anxieties and perceived threats in the illness experience were often neither acknowledged nor resolved in the process of the infection being treated.

Medication treatment is now regarded as sufficiently potent on its own to cure and control the disease, and findings of this study indicate the extent to which this belief has influenced practice. Therefore, correctly prescribing treatment and encouraging patients to adhere to regimens is the basis of tuberculosis management. At the same time, it appears that two sets of patient expectations, regarded as unnecessary or incongruent with current treatment options, are seldom acknowledged or met. One set relates to beliefs and fears

about tuberculosis, and the other refers to felt needs for guidelines on how the patients should be cared for and thereby contribute to their own health improvement. In the light of these findings, treatment of the patient that emphasises the importance of complying with prescribed medication, while minimising or de-emphasising other needs, is inconsistent with holistic, person-centred care.

The view of the patient that emerges from the findings of this study differs substantially from that inferred from much literature and implicit in findings presented in Chapter Seven. Conventionally, the patient is represented as needing to be ordered, persuaded, and sometimes coerced into complying. In contrast, from in-depth, qualitative data collected directly from patients, it is apparent that more commonly their intent is to follow the regimen, and modify behaviour necessary for the recovery of health, to which end appropriate action is taken.

COMPLIANCE IN THE CONTEXT OF ON-GOING HEALTH CARE

Both the literature and evidence from this study suggest that health care practices to prepare and assist ambulatory tuberculosis patients for continuing with prescribed treatment are based on two sets of assumptions. These concern the efficacy of the medication alone to effect cure, and the motivation and ability of patients to follow the regimen. However, by looking at compliance more closely from the point of view of patients, it became apparent that patient and practitioner perspectives do not always coincide. These discrepancies, highlighted by the phenomenological approach, have important implications for health care practitioners, as outlined below. By using the schema of the career of the tuberculosis patient as depicted in Fig 1 (p.18), compliance with a prescribed course of treatment can be seen in relation to the wider context of caring for health, and temporally in progressive stages of the patient career, as shown in Fig 4 (p.169).

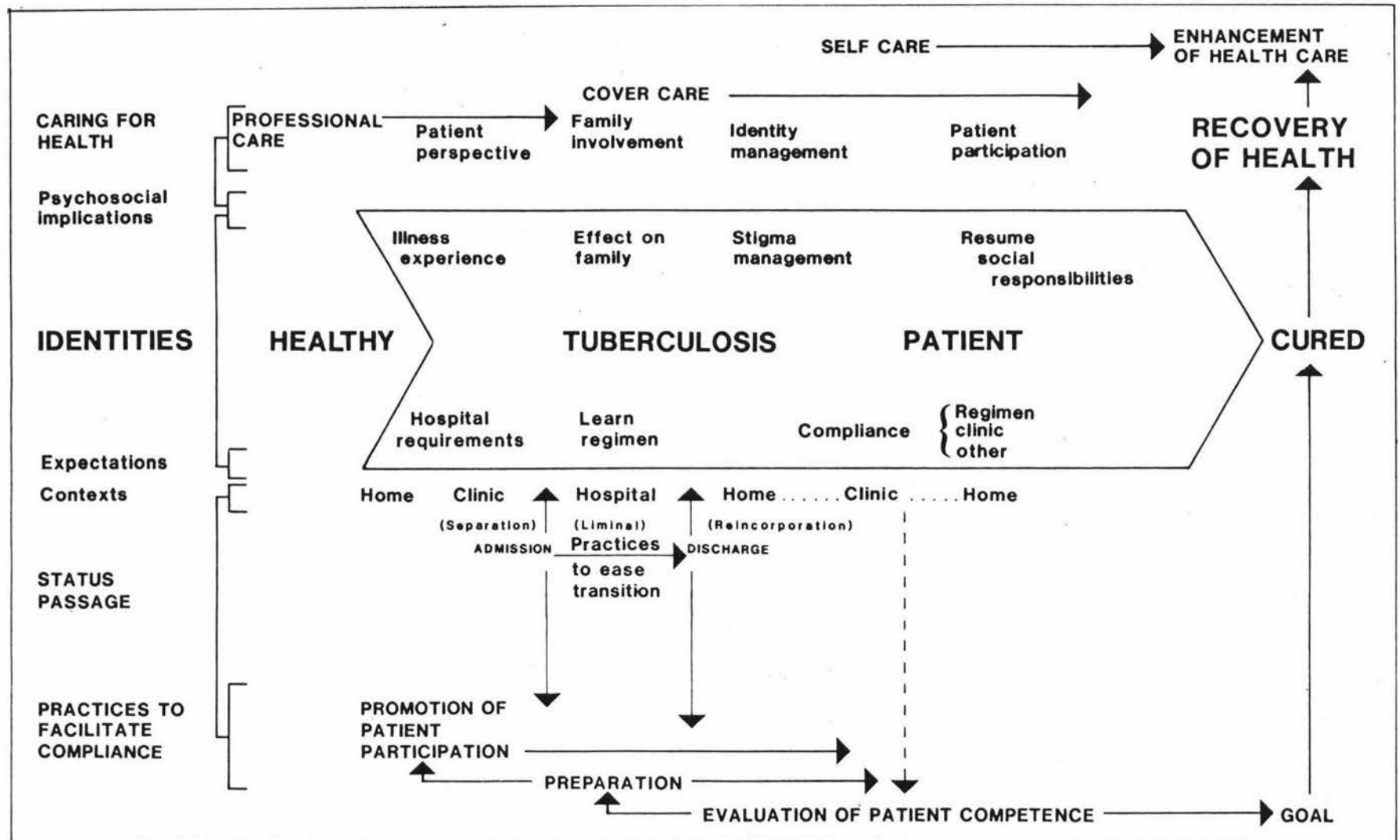


Fig 4: Compliance in Context of the Patient Career

The Context of Health Care:

The Tb patient while in hospital is responsible for taking medication as prescribed, but as an ambulatory patient, following the regimen is no longer the only activity in which the person is engaged. It is evident that health care practice, aimed at preparing the ambulatory patient to manage the regimen, acknowledges neither the effects on compliance of changes in environment nor the extent of involvement of family members in caring for the patient. Implicitly regarding the patient as independent of and unaffected by household and community processes seems an inappropriate approach to encouraging compliance in view of findings of this study.

In addition, there were apparent differences of perception between practitioners and patients regarding the need for guidelines as to how to improve basic health care behaviour. By responding to expressed needs for such guidelines, advantage is taken of the illness event to enhance people's health knowledge and practices at the same time as curing the disease by prescribing treatment. Therefore, the provision of guidelines on caring activities in response to expressed needs is more than simply meeting their expectations and so promoting patient satisfaction. It acknowledges and accepts as relevant and valid, patients' expectations based on an intimate knowledge of their own situations and needs. In the context of the life-span, limitations of the technical expertise of the professional care sector are recognised in relation to basic self-care and cover-care activities that are of lasting importance. Compliance with the regimen is seen as an aspect of self-care necessary for recovery, and thenceforth maintenance of health is influenced by continuing self-care.

The Context of the Patient Career:

A major problem for health care practitioners in enhancing patient compliance is that although the status of ambulatory patient is the crucial stage, contact between practitioners and patients occurs mostly during the in-patient

stage of the patient career. Health care services provided while the patient is in hospital need to be relevant to enable him to comply in the domestic environment. The likelihood of compliance being adversely affected by discontinuities between inpatient and out-patient stages of the patient career is recognised in that the extent of change of patient behaviour at the time of discharge is reduced by making inpatients responsible for taking their medication. Even so, there are significant discontinuities accompanying the change in patient status that are evidently not recognised by practitioners, and therefore patients are not assisted to anticipate them. Along with a reduction in domiciliary supervision of Tb patients, and with practitioner-patient contact in chest clinics being limited by pressure of patient number, the inpatient stage is the remaining period in which practitioners and patients can interact on a continuous basis. There is a need for nursing personnel particularly, as the category of practitioner constantly present in the ward, to make maximum use of the stage in facilitating on-going compliance with health care plans. In subsequent practitioner-patient interaction, checking on patient compliance should be less a matter of policing, and more an evaluation of the effectiveness of health care practices to encourage compliance. This conclusion challenges the medically-oriented purposes of hospitalisation, as outlined in Chapter Five (p.79 f) and highlights the importance of measured efforts during the inpatient stage to ease the transition of the person to the status of ambulatory patient.

COMPLIANCE FACILITATED BY HEALTH CARE PRACTICES

By recognising the stage of hospitalisation as a period of transition for the patient in which there is a need for measures to ease the change in status, the purposes of that period will meet the requirements of a status passage as identified by van Gennep (1960) and outlined in Chapter Two (p.20). The passage from one discreet

identity to the next - in this case, that of healthy person to Tb patient - begins with separation from normal life, which coincides with being admitted to hospital. The status passage, which is liminal in that the person is suspended from normal social activity, is marked in this instance by a physical separation through being hospitalised, or can be marked functionally, e.g. in terms of Parsons' (1951) Sick Role. Having recognised the status passage, there is a need for practices to facilitate the person's transition to the next status. Discharge from hospital marks the change in status to that of ambulatory patient, with reincorporation into social life and the resumption of responsibilities being accompanied by changes appropriate to the new status. These changes, namely, on-going compliance with prescribed medication and related recommendations, have been the focus of this study. By the time the status passage ends, health care practices during that period ought to have prepared and equipped patients for continuing treatment and caring for their health as appropriate to the status of ambulatory patient. Therefore, practices to facilitate compliance are seen in the light of easing the transition of the person to the ambulatory patient stage. Consistent with a person-centred approach, these practices need to be based on factors and processes that are empirically assessed, and the treatment of the specific disease to take place in the broader context of on-going health care. Criteria for determining the adequacy of measures encouraging patient compliance that are related to the concept of status passage, will favour a transition that is characterised by continuity rather than discontinuity.

The hospitalisation stage as a status passage is depicted in Fig 4 (p.169). The time between the person's entry into the health care system, and the commencement of treatment is a critical period in the patient career for promoting in the person a sense of responsibility for complying with the regimen. A positive view of the person as being actively interested in his own health is appropriate to promoting patient participation with a protracted treatment process that may involve lifestyle modifications. Health care practices to facilitate patient compliance that accompany the status passage need to be congruent, on the one hand, with the

positive view of the patient, and on the other, with the needs and situations of ambulatory patients. Finally, after the patient is discharged home, there is a need in health care practice to reinforce compliance with prescribed medication and related recommendations while providing holistic patient care. By assessing patient competence in managing the regimen, the adequacy of health care practices during the status passage can be evaluated.

Specific health care practices suggested by the findings of this study that can be applied during the status passage to facilitate compliance are shown in Fig 5 (p.174). The core principle underlying practices is to reduce discontinuities while enhancing continuities between stages through which the person passes. That a principle of enhancing continuity underlies patient management as presently practised is evident from the system of Individualised Patient Medication. However, findings suggest that this narrow application of the principle should be extended so that the apparent discontinuities between inpatient and ambulatory patient stages be reduced. For example, using such measures as role-play, group discussion, and counselling, patients can be assisted to explore possible difficulties they may personally encounter after discharge. Patients can then be encouraged to develop strategies to remind or monitor compliance before leaving hospital, rather than in response to problems experienced. Patients' knowledge base, acquired through education during the status passage, ought to be sufficient to enable appropriate decision-making in the event of irregular occurrences. It is appropriate to include family members in status passage practices, so that continuity between inpatient and ambulatory patient stages is further enhanced.

RECOMMENDATIONS FOR PRACTICE

The aims of practice in the status passage are:

- 1) to facilitate compliance of the ambulatory patient by reducing discontinuities and enhancing continuities, and by enhancing the capacity of patients to continue

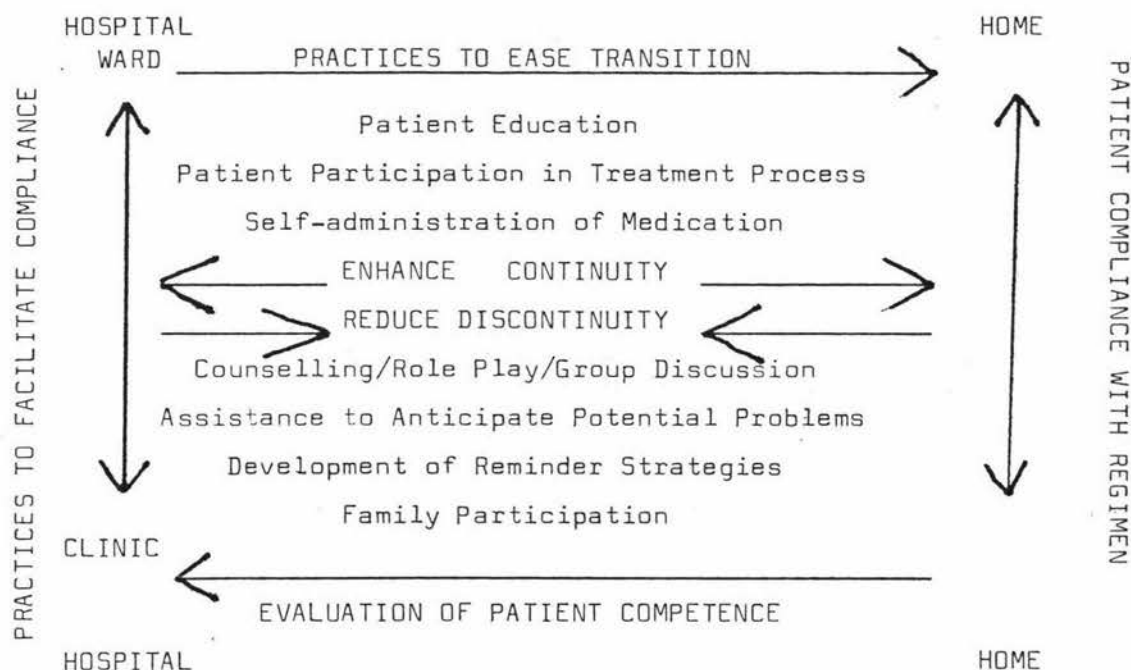


Fig 5: Health Care Practices to Facilitate Compliance

managing the regimen at the same time as resuming social activities.

- 2) to assist patients in improving the level of basic self-care and to provide family members with guidelines for cover-care,

In order to meet these aims, the following recommendations for practice are suggested.

For nursing practice, it is recommended that:

- 1) In view of decreasing domiciliary supervision of patients, nurse practitioners who have contact with Tb patients in hospital wards and clinics recognise the importance of the hospitalisation period for subsequent compliance. In the light of this, measures are necessary to prepare and assist patients for

- compliance with a prolonged course of treatment,
- 2) Nurses in the ward extend the application of the principle of enhancing continuity between inpatient and ambulatory patient statuses along the lines suggested by the findings of this study. There is a need for more innovative approaches to prepare patients for contingency decision-making in domestic environments. Including family members in such activities would further reduce discontinuities.
 - 3) Nurses in clinics develop ways of evaluating the competence of ambulatory patients in managing regimens. This may involve an examination of present job and priorities to enable increased interaction with patients.
 - 4) Closer liaison between ward and clinic nursing staff and, where applicable, with district and public health nurses, needs to be developed in order to evaluate health care practices aimed at facilitating patient compliance, and to modify practices if necessary.
 - 5) The illness event be used to educate patients not only in managing a course of treatment, but in enhancing self-care and cover-care practices. In this respect, the expressed needs of patients and their families for guidelines in caring for health provide occasions for further health education.
 - 6) Particular assistance and support, possibly involving domiciliary supervision, needs to be provided to patients with documented compliance failure, or, as in the case of drug resistance, when consequences of poor compliance are particularly serious.

For other health care practitioners, it is recommended that:

- 1) There is agreement between different practitioners on the kind and emphases of recommendations given to patients particularly in relation to lifestyle modification and health care. This may involve group meetings on a regular basis, and include an examination

of the effects practitioner behaviour may have on patient compliance,

- 2) The complexity of the regimen is minimised by prescribing as simple a regimen and schedule as possible. Patients' perceptions of the complexity of the regimen need to be assessed empirically to provide guidelines for practice, including services offered to assist patients to comply. One aspect of perceptions of the regimen suggested by this study is to look at how medication doses as supplied relate to doses as prescribed,
- 3) The quantity and format by which drugs are dispensed are as manageable as possible, e.g. by dispensing medication in weekly lots,

SUGGESTIONS FOR FURTHER RESEARCH

For nursing research, it is suggested that:

- 1) Further research into patient compliance using different populations of tuberculosis patients, e.g. from contrasting regions or societies, be conducted to strengthen findings of this study through comparison,
- 2) Studies similar to the present study, but using different populations of patients, be conducted. For example, an interpretation of the perspectives of patients taking a regimen that is necessary to sustain life, or is needed indefinitely, or makes greater demands on lifestyle, would further contribute to the understanding of patient compliance,
- 3) A study of the effectiveness of health care practices to facilitate patient compliance, based on the principle of enhancing continuity through the status passage, is needed to establish usefulness,
- 4) Data in the present study on patient education and patient-practitioner interactions have been obtained indirectly from patients' accounts. There is a need to

directly observe these interactions to investigate not only the content, but also the manner, of patient education and related practices, and the extent and means by which nurses promote patient participation in health care plans, in order to determine the effect current practice has on patients' capacity to manage regimen and care for health,

For other health care practitioners, it is suggested that:

- 1) A controlled study of the effectiveness of such systems as Individualised Patient Medication on compliance of ambulatory patients, with a range of regimens for the treatment of a variety of disorders, be conducted, with a view to extending the system within hospitals.
- 2) Research be conducted into the manufacture and packaging of medications to simplify the process of taking tablets, and into the development of tools which patients can use to facilitate and monitor compliance.
- 3) Research is needed to develop ways of assessing and measuring patient compliance in the clinic setting.
- 4) There is a need to empirically establish whether the efficacy of antituberculosis medication to cure the disease can be enhanced by complementary health care measures with a resultant reduction in treatment time, or is reduced by the lack of such measures.

In the region in which the study was conducted there is a continuing population of Tb patients, and therefore a pool of infection in the community. It is therefore suggested that there could be significant gain to public health by implementing practices recommended on the basis of findings of this study. By facilitating the transition of the hospitalised patient to the status of ambulatory patient, with full responsibility for continuing treatment without the direct support and supervision from health care practitioners, the possibility of treatment failure through poor compliance is reduced, and control of the disease is made more effective,

APPENDIX 1

EXCERPTS FROM INTERVIEWS TO GIVE EVIDENCE OF PROCESS OF THE STUDY

- (a) Excerpts from first, second and third visits to demonstrate the pattern that occurred:

The interview was with Mrs M., a Maori woman, with pulmonary tuberculosis. Interviewer's comments are signified by "I".

VISIT 1: (documented in field-note form).

Explained purpose of visit - readily agreed to participate. A youth was about, a nephew - Mrs M. would prefer that he wasn't involved. Didn't object to her husband participating, though. When I explained by reason for visiting, she immediately started talking about the difficulties in taking so many medications: "I'm a diabetic too, you see, I only got Tb at the beginning of the year. I take them when I get up, then after breakfast, and 9 o'clock, and lunchtime, and tea time. You see, that's a lot of pills." (Detailed how many, and at what time - and made several errors which she was correcting at the same time). "You see - you have just reminded me now - I haven't taken them this morning. Dummies like me - it's really hard to remember...Yes, I'd be very happy to talk to you. I love telling people about my illness and so on - talking helps to get it all sorted out." Before I left she signed the consent. I asked when I could come again. "Tomorrow at 10 o'clock I have to go and have a chest x-ray, and Friday I'm out too." "Would tomorrow early afternoon be alright?" "They wouldn't be that long, would they? (referring to chest clinic). Come about 12." "I'll come a little later, if that's alright?" "That'll be fine. We're always in."

VISIT 2: (excerpts from transcription of tape).

I: How did you get on at the clinic today?

Mrs M: That was okay,

I: You saw the doctor?

Mrs M: I saw Dr X today; usually I see a specialist, Dr Y. He was there - I saw him there. But he didn't see me. (Sounded slightly upset). But, ah, this other doctor come in and got me. They they sent me for an x-ray again. They showed me my x-rays. They are much better than when I was

in there. It's cleared up. But in the first one you can see where the spots are, with pneumonia, bronchitis, Tb, I had everything.

I: Mmm.

Mrs M: Well, I was telling them about the medicine, you know. Sometimes you forget. And he said to me, "No matter what, you have to take them." And I said, "It's not that I have missed a day, no, I still take them, but not at the time I'm supposed to take them. Half an hour before breakfast, and then, half an hour after breakfast. That means 7 o'clock the first lot, 9 o'clock, then 12 o'clock, then 6 o'clock.

I: Yes. And is that why he gave you a "telling off?" (The first thing Mrs M. greeted the interviewer with was that she had received a "terrible telling off.").

Mrs M: And the weight. When I come out of there, I was 13 stone. Now I'm 14½ stone. And that's not going to do me any good because I'm a diabetic. And if the diabetic doesn't go down, the Tb won't; I'll get Tb again.

I: Is that what he said?

Mrs M: Yes. And if I don't watch out, I'll die soon.

I: Is that what he said?

Mrs M: Yes.

I: He really told you that?

Mrs M: Yes, he really did. And he told me to shout myself to Weight Watchers. To go to the Weight Watchers. So I couldn't imagine myself going to Weight Watchers. It's a waste of money because I'm cooking all the time, you know. What I've done and told them (household) now, they'll have to go and cook their own meals. I'm not going to do any cooking.

I: And what are you going to live on?

Mrs M: I've got - bought myself - some lettuce and tomatoes. You can get them now. And in the morning I'll have diabetic fruit. And one piece of toast.

I: Do you have insulin injections?

Mrs M: No, diabetic pills. Two, three times a day.

I: And the Tb ones as well?

Mrs M: Yes. The first three is at 7 o'clock, and the next 3½ at 9 o'clock. And then I start my diabetic ones at 9 a.m.

I: Why are the Tb ones like that?

Mrs M: Well, when I started my medication when I was in hospital, this is how they started me off. Three before breakfast, at 7 a.m., and after breakfast, at 9 o'clock, I take the other three, and then the diabetic ones on top of the Tb ones. You see, that's a lot of pills.

I: It is a lot of pills. How many altogether each day?

Mrs M: (Counted up) - That's 12½ pills a day.

I: Are they big, or little?

Mrs M: They are big. Would you like to see them?

I: Yes, I would. Where do you keep them?

Mrs M: In my bedroom, in the drawer.

(Visits 3 and 4 - visitors present. Therefore arranged another time).

VISIT 5: (Field notes written immediately after interview).

Mrs M. said she was going to the Labour Dept. today. Has own transport, so can go to work anywhere in Auckland, day or night. Has good references for all canteen work - never been sacked. Then she said that the trouble is, she wants to be well before she starts work, as it's no good starting, and then stopping again because you are sick.

I: Do you think you might get ill again? Are you still not well?

Mrs M: Sometimes I get this awful pain, round here (pointing to left upper chest and shoulder, both front and back). And sometimes I wake up at night soaked, sweating - my hair all wet.

I asked if she had told anyone about this. (She had mentioned a recent visit by the public health nurse). Had she told the nurse when she was there?

Mrs M: No, not sweating all the time - just a few minutes. Not every night.

Asked what the nurse had come for.

Mrs M: She asks me how I'm doing, about my medication, if I'm taking it every day. If I run out, she will get more for me. But I said "It's alright, the doctor at the hospital gives me enough for three months." She asks how I am.

I asked if she told her about the chest pain then.

Mrs M: I hadn't had the chest pain then.

I: Do you think it would be a good idea to ring her up if you are worried? (She had already said too expensive to go to G.P., as no wages at present).

Mrs M: She said to ring up any time I wanted anything. And that she would be back, drop in again. (Rustled through a rack of memos, letters, bills - couldn't find what she was looking for, apparently. Eventually located a card on which PHN had written her name and phone no.).

I asked about the defaulted admission to National Women's just before Christmas - she hasn't phoned or contacted them, and neither have they her. She said that if they want her, she will go in.

Mrs M: It was just that it was right on Christmas, and I thought if they find anything more I may have to stay in and miss out on Christmas. But they are probably mad at me.

Still has lower abdominal pain. (Noted that when she coughed, she always covered her mouth with her hand).

Mrs M. informed me that she had told the public health nurse about my visits. Therefore I contacted her, to explain the purpose of my visits. She discussed her client's anxieties about her weight. Also said:

"We are only required to visit Tb patients while they are on medication, and make sure they are still taking them." I asked if she was satisfied that Mrs M. was taking hers regularly. "Oh yes, like a lamb. She's marvellous."

- (b) An example of cross-checking pieces of information with another member of the household in order to verify data:

Mr B. (being treated for pulmonary Tb) who was on his own in the house during the main tape-recorded interview, related the following:

Mr B: That's another thing I do. Out of those big bottles, I take out enough (tablets) for the week. I have two bottles, see.

I: Whose idea was that?

Mr B: Mine - mine! I just thought - I had no way of knowing had I missed it, you know?

I: Yes, I have wondered about that.

Mr B: No way of checking up at all. So, every Monday I take 14 of one, and 7 of the other, and put them in the second bottles.

I: So, you are pretty careful about it, aren't you?

Mr B: Well, it works.

I: Does your wife do the same with all her pills? (Mr B. had already stated that she was on antihypertensive medication).

Mr B: NO! Don't believe that - women! They don't have a system!

I: Does she manage to take hers successfully without a system?

Mr B: Oh, she often doesn't know if she took 'em or if she didn't. She will be sitting down and say "Did I take my pills this morning?" And I'd say "How the devil would I know!"

At the final interview Mrs B. was also participating:

Mrs B: I don't have to worry about him! He's doing everything he ought to. He's a character, that one. He hasn't missed once! With counting them out and so on. As for me - I'm forever going around saying "Now have I taken them this morning or not?" I'm alright, so long as I take them when I first get up. Otherwise, I've had it - I never know.

I: You could do something like your husband does.

Mrs B: That's what he says! But I'm not going to give in to him!

- (c) Excerpts to demonstrate identification of themes in initial analysis of data, and subsequent further exploration or verification:

Miss C. was being treated for pulmonary Tb. Early in the tape-recorded interview she attributed symptoms to the medications:

"I mean, I felt fine before I got in there (hospital) and then I felt dreadful. I'm sure it was the drugs that made me feel terrible - I slept a lot, I was asleep all day and all night, I was really tired. And I was also quite depressed for a couple of days..." (She claimed that she was still experiencing side effects).

Later in the same interview she stated:

"Because I don't really like taking these pills. I hate going up to the chemist to get them - the chemist is a really nice guy, but I still feel really embarrassed going in there and getting them."

In discussing the period of time leading up to being diagnosed with Tb, she said:

"The last couple of years have been quite tough emotionally, and the beginning of last year was really hard. But it's settled down, and things have sorted themselves out. After a while I got over that, and started looking after myself, and making sure I was getting more sleep, eating... and building myself up with extra vitamins, kelp tablets, and bits and pieces like that. And I actually did feel better, just felt really tired... I'm finding I make myself eat more than before. I find also I sleep a lot more because I'm a lot tired."

I: What do you attribute that to?

Miss C: The tablets. I'm quite sure of it, that that's a lot of it...

After a provisional analysis of the data, the researcher was interested in the apparent contradiction between an emphatic dislike of taking antituberculosis medication, and with self-medication with vitamins and other tablets. The issue was raised in the subsequent interview:

(From field notes):

"She feels she is tired and lethargic as a side effect of the medications, which is one reason why she doesn't like taking them - she hates feeling 'zoned out' all the time. And 'It isn't very nice to have to take medications.' I asked

her 'But you don't object to vitamin pills?'
'Oh no - those are healthy. If you are in a
rush and miss a meal or something, they will
tide you over till the next one. It is those
other drugs that have side effects.'"

It is possible that tiredness is a side effect of medications -
one other participant also reported being tired, although he
attributed this to the effects of the disease, rather than the
effects of medication. Miss C. had made a number of comments,
denying that she had active Tb, and asserting that treatment is
unnecessary. It was concluded therefore that her objections to
taking medication were related to her negative feelings about
having Tb, to unpleasant effects attributed to the medication,
and to being obligated to take the medication, rather than being
opposed to taking all forms of medication per se.

APPENDIX 2

INFORMATION PAMPHLET FOR PATIENTS

See inside back cover for a copy of the pamphlet entitled
"The Treatment of Tuberculosis".

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THE TREATMENT OF TUBERCULOSIS

For the information and guidance of patients

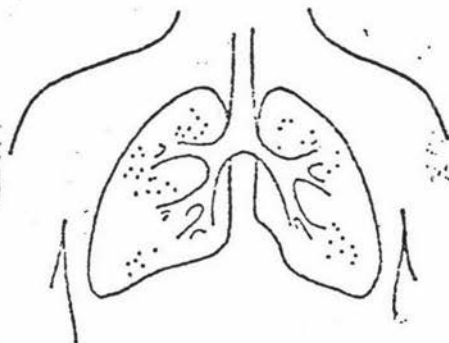
WHAT IS TUBERCULOSIS (Tb) ?

Tuberculosis is an infectious disease which most commonly affects the lungs, although it can also occur in other parts of the body.

Untreated, this is a serious disease, and at one time a high proportion of those who contracted it died as a result. Many of the others had to spend a long time in hospital and a long time off work.

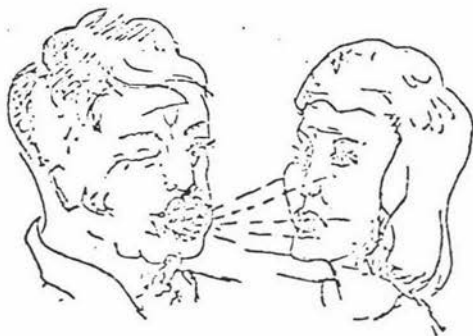
Great advances have been made in the prevention and treatment of this disease, but about 20 new cases a month are still notified to the Health Department from Auckland.

When notified of a new case, the Health Department will arrange to check the close relatives and contacts of the patient, with x-rays or skin tests, to make sure that no one else in the family is affected.



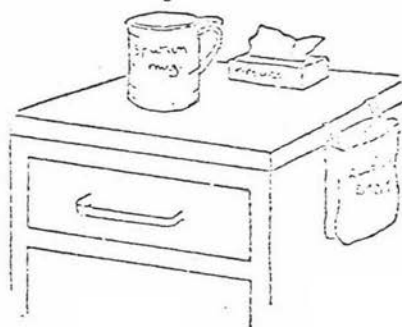
HOW DOES TUBERCULOSIS SPREAD?

Tuberculosis is spread from one person to another. When the lung is diseased, its secretions (i.e. sputum or spit which is coughed up, or droplets from the mouth) contain the tubercle bacillus. A patient with tubercle bacilli in the sputum is infectious.



HOW CAN YOU HELP TO PREVENT THE SPREAD OF TUBERCULOSIS?

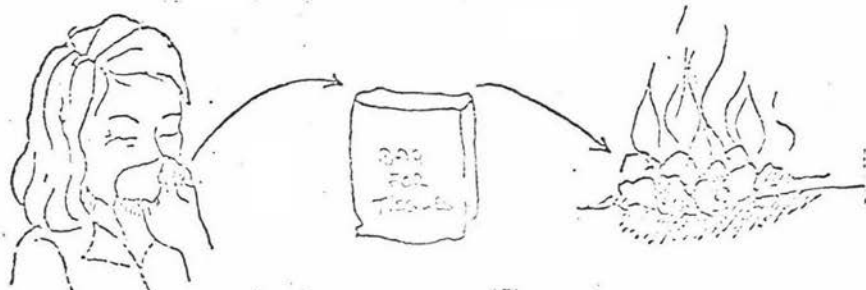
1. You have been admitted to hospital to protect your family and the general public from close contact with you while you are infectious, and to establish you on the correct treatment for Tb.
2. On your locker is a sputum mug. Please use this mug whenever you cough up sputum. The mug will be emptied daily or more frequently if necessary. The contents are burnt to ensure that the tubercle bacilli are destroyed.



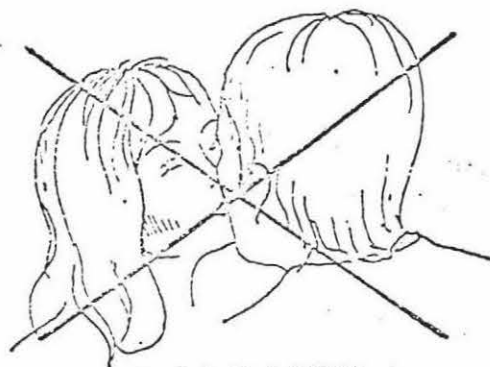
Spit only into the sputum mug or tissues provided, for these can be burnt.

Remember - your spit is infectious and can infect others with tuberculosis.

3. You also have a supply of paper handkerchiefs. Please use these whenever you cough, sneeze or blow your nose. These tissues are burnt daily. DO NOT USE COTTON HANDKERCHIEFS.



4. PLEASE COVER YOUR MOUTH WHENEVER YOU COUGH.
5. DO NOT kiss any member of your family when you see them. You could give them Tb.



6. Children are much more likely to catch tuberculosis from you than adults are, and are apt to develop the most serious forms of the disease. For this reason we do not allow children to visit the ward.



While you are in hospital you may ask for permission to walk about the grounds when you feel well enough, but please advise the nursing staff before leaving the ward. Infectious patients must not enter the Coffee Shop or Post Office areas. No patient is allowed to leave the hospital grounds unless permission has been given by the doctor.



HOW IS TUBERCULOSIS TREATED?

There are several drugs which are effective against the disease. The most commonly used are:-

Streptomycin

I.N.H. or Isoniazid)

Rifampicin)

Rifinah)

Ethambutol)

All tablets given one to four times a day.

Your doctor will have chosen those drugs he thinks most suitable for you. No matter which drugs he has chosen, you will have at least two types when you start having treatment. Treatment with drugs must continue for a long period, ranging from 1 to 2 years. It is most important that you take the full dose regularly throughout this time, to prevent a recurrence of the disease.

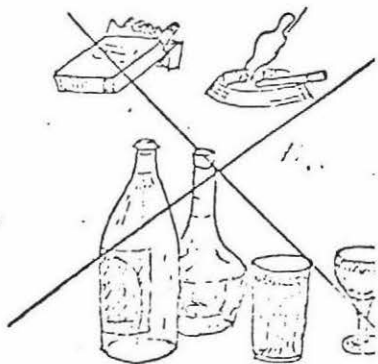


If you reduce the number of tablets or have gaps in your treatment, the tubercle bacillus tends to develop a resistance to the medication (drugs) and will begin to grow again. If this happens, you may become infectious again and will require further treatment. A second course of treatment is less likely to be effective than a properly conducted first course.

NOTE: When you begin taking some of the tablets, such as Rifinah or Rifampicin, you will notice that your urine may change to a bright orange colour. DO NOT BE ALARMED. This is a normal reaction.

WHAT CAN YOU DO TO ASSIST IN YOUR RECOVERY?

1. Smoking lowers the body's resistance to tuberculosis. You are advised to stop smoking, or at least reduce the number of cigarettes you smoke to less than 10 a day.
2. Alcohol is not permitted on hospital premises. It is unwise to mix alcohol and medicines - you may get an unpleasant reaction.
3. Rest in adequate amounts is necessary, and tiredness is to be avoided. Although you are allowed to be up and dressed, you must have some rest during the day.
4. Worry should be avoided if possible. The hospital's Medical Social Worker and the Tuberculosis and Chest Diseases Association are available to give you assistance with personal, domestic or financial problems. Please advise your Charge Nurse if you would like this assistance.



HOW LONG WILL YOU BE IN HOSPITAL?

You will remain in hospital until you no longer have tubercle bacilli in your sputum and your chest x-ray is showing signs of improvement. This does not mean that you are free of the disease, but that the infection is under control. When you reach that stage it is not considered very likely that you will pass the disease on to other people.

Most patients will remain in hospital for approximately 2 to 4 months and will be able to return to work a month or so later.

Your doctor will tell you when you can have weekend leave from the hospital. This will rarely be granted earlier than 4 weeks from the time of admission, and then only if your doctor considers you are no longer infectious.

PROGRESS REPORTS

Your doctor will give you information regarding your progress towards health when you ask him.



DISCHARGE

When you are discharged you will be given an appointment to be seen in the Chest Clinic a month later.

At that visit your doctor will probably decide when you can return to work. (His decision will be influenced by your progress and by the type of work you do.) From then on you will attend Chest Clinic every 2 to 3 months while you are having treatment, i.e. for 18 months to 2 years. After completing your treatment you will be seen at intervals which will lengthen gradually from 3 months to 12 months.

There are two important things to remember when you return to your home.

1. PROTECT YOURSELF

Continue to take all your tablets. These will be given to you at every visit to Chest Clinic.

2. PROTECT OTHERS

Remember how tuberculosis is spread. Cover your mouth when you cough, at all times. You may still have occasional tubercle bacilli in your sputum until you have completed your treatment.



Rifampin and Rifampicin may interfere with the action of the contraceptive pill and reduce its contraceptive action.