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COMPLIANCE
FROM THE PERSPECTIVE
OF TUBERCULOSIS PATIENTS

A thesis presented in partial
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of Master of Arts
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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 referrent 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 readibility. 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.