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COMPLIANCE
FROM THE PERSPECTIVE
OF TUBERCULOSIS PATIENTS

A thesis presented in partial
fulfilment of the requirements for the degree
of Master of Arts
in Nursing Studies at
Massey University

Nicola North
1983
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.
ACKNOWLEDGEMENTS

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Irena Madjar contributed enormously by supervising the study itself, and all that went before in setting it up. I am particularly grateful to her, and to Dr Norma Chick, who took over the supervision of the writing of the thesis during Irena's absence. Norma's supportiveness in her advisory role during that period has been greatly valued.

I am grateful to Mrs Jill Cheer, who went over and above the call of duty in typing the manuscript, and also to Mr Kees Korndorffer for illustrations.

I wish to thank those working at the Health Department and hospital in the district in which the study was conducted, whose cooperation enabled the research to be carried out. The staff of the Chest Clinic were involved to the greatest extent, and I am grateful for the cheerful assistance provided there.

Finally, this thesis could not have been carried out without the participation of the patients themselves, and their families. I am truly indebted to them for their willingness to give of their time and for sharing their experiences and perceptions.
# TABLE OF CONTENTS

Abstract
Acknowledgements
Glossary of Terms

## PART 1

### Chapter 1

**AIM OF THE STUDY**

**BACKGROUND TO THE STUDY**

- Need for Research into Compliance
- Current state of Knowledge about Compliance
- Personal Concern about Compliance

**COMPLIANCE AS A VALID CONCERN FOR NURSING**

**SCOPE OF THE STUDY**

**STRUCTURE OF THE REPORT**

### Chapter 2

**PROFILE OF TUBERCULOSIS: DISEASE AND MANAGEMENT**

**TRENDS IN THE EPIDEMIOLOGY OF TUBERCULOSIS**

- Infectivity and Susceptibility
- Tuberculosis in New Zealand

**MANAGEMENT OF TUBERCULOSIS**

- Tuberculosis as a Public Health Problem
- Treatment of Tuberculosis

**PSYCHOSOCIAL IMPLICATIONS OF HAVING TUBERCULOSIS**

- The Threat of Having Tuberculosis
- The Stigma of Tuberculosis
- Perception of Illness

**THE CAREER OF THE TUBERCULOSIS PATIENT**

- Identity and Expectations of the Ambulatory Tb Patient
- Status Passages
- Status of the Ambulatory Tb Patient

**SUMMARY**
Chapter 3

REVIEW OF LITERATURE ABOUT COMPLIANCE

Meaning of the Term "Compliance" 24

THE PROBLEM OF NONCOMPLIANCE

Early Contributions to Compliance Literature 25
Present State of Knowledge about Compliance 26
- a Summary
Consequences of Compliance Failure 28
Issues in the Measurement of Compliance 30
Magnitude of the Problem of Noncompliance 32

DETERMINANTS AND PREDICTORS OF NONCOMPLIANCE

Demographic Characteristics of Patients as a Factor in Compliance 34
The Illness and Regimen as Affecting Compliance 35
Sociobehavioural Characteristics of Patients in Relation to Compliance 37

STRATEGIES FOR IMPROVING COMPLIANCE

Educational and Counselling Strategies 42
Behavioural Strategies 44
Strategies Concerned with the "Health Care Service" 46

COMPLIANCE IN RELATION TO CHANGES IN HEALTH CARE

Compliance with Rehabilitative Services 47
Patient Compliance with Long-term Treatment Plans 48
Patient Compliance as an Outcome of the Practitioner-Patient Interaction 50
Potential of Nursing Practice to Promote Patient Compliance 52

THE PERSPECTIVE OF THE PATIENT ON COMPLIANCE

SUMMARY AND CONCLUSIONS 55

Chapter 4

STUDY DESIGN AND METHODOLOGY 57

THE INTERPRETIVE APPROACH 57

THE RESEARCH QUESTIONS 60

RESEARCH DESIGN

Field Research Method 61
Objective Measures of Compliance 62

DEFINITION OF TERMS 63

CRITERIA FOR SELECTION OF PARTICIPANTS 64

ETHICAL CONSIDERATIONS 64
Chapter 7  PERCEIVED PRACTITIONER CONCERN AS A FACTOR IN COMPLIANCE

CONCERN WITH COMPLIANCE WITH MEDICATION
  Information about the Regimen 118
  Content of Teaching 120
  Dissatisfaction with Information 126
  Perceived Concern with Compliance after Discharge 127

CONCERN WITH COMPLIANCE WITH OTHER RECOMMENDATIONS
  Proscriptive Recommendations 134
  Recommended Measures to Protect Others 139

CONCERN WITH COMPLIANCE WITH CLINIC APPOINTMENTS

SUMMARY AND CONCLUSIONS

Chapter 8  THE ILLNESS EXPERIENCE AS A FACTOR IN COMPLIANCE

SUBJECTIVE EXPERIENCES OF HAVING TUBERCULOSIS
  Impact of the Patient's Illness on the Family 147
  Perceived Seriousness of Tb 148
  Stigma Associated with Tb 152

CARING FOR HEALTH
  General Health Care Measures Advised 159
  Perspectives and Expectations of Patients 162

SUMMARY AND CONCLUSIONS

Chapter 9  CONCLUSIONS AND IMPLICATIONS OF THE STUDY

A SUMMARY OF PATIENTS' PERSPECTIVES ON COMPLIANCE

COMPLIANCE IN THE CONTEXT OF ON-GOING HEALTH CARE
  The Context of Health Care 170
  The Context of the Patient Career 170

COMPLIANCE FACILITATED BY HEALTH CARE PRACTICES

RECOMMENDATIONS FOR PRACTICE

SUGGESTIONS FOR FURTHER RESEARCH
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. 178
(b) An example of cross-checking pieces of information with another member of the household in order to verify data. 182
(c) Excerpts to demonstrate identification of themes in initial analysis of data, and subsequent further exploration or verification. 183

APPENDIX 2  INFORMATION PAMPHLET FOR PATIENTS 185

BIBLIOGRAPHY 186
LIST OF TABLES AND FIGURES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Demographic Characteristics of Participants of the Study</td>
<td>67</td>
</tr>
<tr>
<td>Table 2</td>
<td>Prescriptions and Recommendations Received by Patients</td>
<td>83</td>
</tr>
<tr>
<td>Table 3</td>
<td>Rates of Patient Compliance in Response to Medical Recommendations</td>
<td>87</td>
</tr>
</tbody>
</table>

| Figure 1    | The Career of the Tuberculosis Patient                                       | 10   |
| Figure 2    | Scale for Self-Rating of Compliance Behaviour                               | 62   |
| Figure 3    | Patient Compliance in Relation to Perceived Barriers-and Response            | 108  |
| Figure 4    | Compliance in Context of the Patient Career                                 | 169  |
| Figure 5    | Health Care Practices to Facilitate Compliance                              | 174  |
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Persons who have entered the health care system, and consulted practitioners within that system.</td>
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<tr>
<td>Ambulatory Patient</td>
<td>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.</td>
</tr>
<tr>
<td>Practitioner</td>
<td>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.</td>
</tr>
<tr>
<td>Regimen</td>
<td>The treatment plan, that includes prescribed medication, and other recommended therapy and practices, are included in this term. &quot;Medication regimen&quot; refers to prescribed medication only.</td>
</tr>
<tr>
<td>Health Care Plan</td>
<td>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.</td>
</tr>
<tr>
<td>Participant</td>
<td>The twenty-two tuberculosis patients who agreed to participate in this study.</td>
</tr>
<tr>
<td>Researcher</td>
<td>The nurse-researcher who conducted the study.</td>
</tr>
</tbody>
</table>

### 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.