The care of chronic illness in general practice

A Thesis Submitted for the Degree of Doctor of Philosophy

of the

Australian National University

1998

Carmel Martin
MBBS MRCGP FAFPHM MSc
Dedication

I would like to dedicate this thesis to my children, Alanna, Matthew, John-Paul and my husband Kevin who suffered, albeit cheerfully, because of the time spent on my thesis. Kevin provided unflagging cheerfulness, encouragement and support. I would also like to acknowledge the assistance of my aunt Lorna who minded my children in many school holidays in order to allow me to work on the thesis. I thank my parents for allowing me to have an open mind, read extensively and hold forthright opinions as a child.

On the academic side, Professor Bob Douglas, has been an optimistic, inspirational and ever pleasant mentor who generously give his time when I required it. Bob was patient, yet critical in a positive way. Jeanne Daly opened up this area of research for me and challenged me with her intellectual strength in the initial stage of the project. Dorothy Broom became a supervisor in a later stage. Robyn Attewell has been a most diligent and helpful source of statistical advice. I would particularly like to thank my valuable friend and adviser Chris Peterson who has given me much technical and academic advice and insight.

Professor Ian McWhinney (Emeritus) without knowing it, has excited an interest in the theoretical basis of general practice underpinning chronic illness care. I have attempted to follow in his footsteps. At the other end of the spectrum, I have also attempted to emulate Dr Jane Leaver, (now retired) Consultant Public Health Physician, who demonstrated the practical implementation of models of health care that were centred around the needs of the frail aged and chronically ill in Inner London.

Finally, I would like to thank three groups who have unwittingly provoked this thesis. My general practice patients and informants from self-help groups with unhappy or difficult chronic illness experiences challenged me to search for new or different models of chronic illness care. I would like to thank the staff of the renal unit at (the then) St Paul’s and St Phillip’s Renal Hospital in Central London who cared for me when I was ill and supported me when I was ‘healing’.

Dr Carmel Martin
Statement of originality of the work

This thesis is my original work. This work has not been submitted for any other degree.

It is not the work of any other researcher, unless explicitly stated in the body of the thesis.

Dr Carmel Martin
Abstract

Internationally, governments are attempting to rationalise the care for those with complex chronic conditions. In Australia, general practice is central to this initiative. This thesis examines the care of chronic physical disease seen in everyday general practice. Exploratory focus groups with chronic disease self-help group members and general practitioners were conducted. They raised concerns that adequate care was unevenly distributed, difficult to access (or provide) and that there were often problems with both clinical and psychosocial aspects of care. Nomenclature and framework around chronic disease and illness are confusing, yet they shape the responses to chronic illness of the ill themselves, their medical providers and society.

This thesis progresses from an analysis of constructions of chronic disease and illness in medical care to an examination of how such ideas are translated into the general practice system. Constructions of chronic disease and illness in the literature vary according to disciplinary perspective. They centre on professional clinicopathological disease models with diagnostic and management actions in biomedicine. There are no universally accepted classifications of care for individuals who experience chronic illness.

Biopsychosocial theory in academic general practice promotes the importance of mind, body and emotions in disease and illness, drawing from clinical and social research paradigms. A series of macro- and micro-level studies explored the understandings and practice of biopsychosocial care of chronic disease and illness in everyday practice.

General practitioners in a national survey described chronic physical disease consultations (a significant component of their work) that were managed principally in the biomedical or disease paradigm with little psychosocial care. Chronic disease consultations, with or without psychosocial co-morbidity, were not longer than average, further indicating that psychosocial care was not routinely provided.

A sample of general practice attenders with chronic conditions described a significant burden of both physical and psychosocial morbidity, despite reluctance to assume a sick role. Clinical competence, personal support, spending time and dedication were very important general practitioner qualities. Dissatisfaction with their general practitioner related to the structure of their care. Their general practitioners, when interviewed, wanted to meet professional and patient expectations of clinical competence. Responses to patients’ personal psychosocial needs were individualistic. They ranged from avoidance to enthusiasm, rather than being a common professional construction based on evidence. All concurred that the health system was inappropriately structured.

Problems with chronic illness care start with fragmented theoretical understandings and the lack of an appropriate evidence base. This is compounded by a health system that is driven by specialised disease models rather than biopsychosocial generalism. A chronic illness model, incorporating a social support framework with practical applications to shape the discipline of general practice and the structure of the health system, is developed.
Publications


Table of Contents

Part 1. The nature of chronic illness and disease. Theoretical frameworks

Chapter 1 Approaching the study of chronic disease and illness in Australian general practice ................................................................. 1
   Abstract ...................................................................................................................... 1
   Introduction ................................................................................................................ 1
   Exploratory focus groups .......................................................................................... 2
   Formulation of the thesis approach .......................................................................... 6
   Research questions for the thesis ............................................................................. 8
   Aims, objectives and methodological approaches ...................................................... 9
   The emerging discipline of general practice - intellectual and scientific ................. 9

Chapter 2 Defining chronic disease and illness ..................................................... 11
   Abstract .................................................................................................................... 11
   Defining terminology ............................................................................................... 11
   Chronicity ................................................................................................................ 11
   Disease, illness, sickness and condition ................................................................... 13
   Qualifications .......................................................................................................... 14
   Defining and framing illness - non-disease based systems ....................................... 15
   Biopsychosocial approaches .................................................................................... 16
   A social psychological approach ............................................................................. 17
   Empirical approaches to biopsychosocial frameworks for chronic illness ............... 17
   Linear and complex systems ................................................................................... 18
   The experience of illness ......................................................................................... 20
   Identifying a framework for understanding chronic illness in general practice ......... 21
   Defining chronic illness for general practice ........................................................... 23

Chapter 3 Understanding constructions of chronic illness and disease ................ 25
   Abstract .................................................................................................................... 25
   Introduction .............................................................................................................. 25
   Understanding social constructivism and social theory ............................................ 26
   A social constructivist perspective of chronic illness and disease ............................ 27
   The experience of illness and quality of life in chronic illness .................................. 29
   Trajectories of illness .............................................................................................. 30
   Social responses to chronic illness - roles and responsibilities ............................... 31
   Constructions of disease ......................................................................................... 33
   The biopsychosocial model: a way forward ............................................................ 34
   Discussion ................................................................................................................. 34
Part 2. What happens in practice. The Microlevel. People with chronic disease and illness attending general practice

Chapter 7  A study of general practice attenders

Abstract................................................................. 87
Identifying chronic illness using quantitative and qualitative approaches ........................................ 88
Aims.................................................................. 89
Methods: Common to Chapters 7, 8, 9, 10 and 11 ...................................................... 89
Selecting general practitioners............................................. 89
Questionnaire for general practice attenders on repeat prescriptions ........................................ 90
Selecting people on long-term repeat prescriptions ...................................................... 91
Statistical approach and methods.................................................. 93
Results of the survey of general practice attenders on repeat prescriptions .................. 97
Disease and health-care profiles of general practice attenders on repeat prescriptions .......... 97
Repeat prescriptions......................................................... 98
Demographic profiles ........................................................ 98
Patterns of service use ...................................................... 99
Morbidity or illness burden: the SF-36 .............................................. 100
Discussion Do repeat prescriptions identify people with chronic disease and illness? ......... 105

Chapter 8 ‘Naming and framing illness and disease’: experiences of people on long-term repeat prescriptions

Abstract................................................................. 107
Experiences of disease, illness and treatment ................................................................. 107
Interviews with a subset of consecutive GP attenders on repeat prescriptions .......... 107
Methodology and participants................................................................. 108
Analysis................................................................ 110
Limitations of the approach taken ................................................................. 111
Results................................................................ 112
Having chronic illness ................................................................. 112
Perceptions of illness and morbidity burden in general practice attenders - discussion .... 127

Chapter 9 Understanding satisfaction and need in relation to general practice care of patients with chronic disease and illness

Abstract.................................................................. 129
Introduction...................................................................... 129
Categorising need and illness impact felt.......................................................... 130
The Illness Impact Scale.................................................................. 130
The Felt Need Scale.................................................................. 131
The Met-Need or Dissatisfaction scale .................................................. 132
Correlations, logistic regression and hierarchical loglinear models - methods ........ 134
Results................................................................ 135
Participants Felt Needs or expectation of general practitioners ......... 135
Correlations................................................................ 136
Understanding patterns of Dissatisfaction ........................................ 136
Discussion................................................................ 140
Development, reliability and validity of scales of Dissatisfaction,
Felt Need and Illness Impact Scales .................................................. 140
Dissatisfaction and the structure of general practice care - continuity and support ........ 142
Chapter 10 Patient experiences of Felt Needs and Met Needs (satisfaction) in relation to general practice care .............................................................. 145

Abstract ................................................................................................................. 145
Introduction .................................................................................................................. 145
The role of the general practitioner ............................................................................. 146
‘Felt need for clinical and technical skills’ ................................................................ 146
‘Felt needs for a supportive personal relationship’ ....................................................... 147
‘Felt need for a general practice to provide a supportive care structure’ ..................... 148
Dissatisfaction ............................................................................................................. 149

Chapter 11 Responding to chronic illness: general practitioners .......... 157

Abstract ....................................................................................................................... 157
General practitioner narratives of chronic disease and illness: ..................................... 157
Naming and framing illness and disease’ Perceptions of chronic care .............................. 157
Responding to and caring for chronic illness ................................................................. 164
The pain of practice .................................................................................................... 168
Time ............................................................................................................................. 173
Discussion ..................................................................................................................... 174

Part 3. Addressing the problematic nature of chronic illness care

Chapter 12 Social support—an overarching framework for clinical care .................. 181

Abstract ....................................................................................................................... 181
Introduction .................................................................................................................. 182
Developing a social support construct ........................................................................... 182
The ‘art’ of clinical expertise .......................................................................................... 183
Social support theories—linking social, psychological and physiological processes ....... 183
Social support and health outcomes .............................................................................. 184
The doctor-patient relationship, social support and general practice care ...................... 185
The meaning of social support ....................................................................................... 187
Discussion ..................................................................................................................... 188

Chapter 13 Developing and implementing operational models of chronic illness care ................................................................. 191

Abstract ....................................................................................................................... 191
The problematic nature of chronic illness care ............................................................. 191
Difficulties in managing both the disease and the illness ................................................ 193
Theory .......................................................................................................................... 193
Illness experience, professional responsiveness and social constructions of illness in biopsychosocial domains ................................................................. 193
Implementing biopsychosocial care incorporating support principles .......................... 196
The practitioner ............................................................................................................ 196
The consultation .......................................................................................................... 196
The structure of the practice in relationship to the health system .................................... 197
The health care system ................................................................................................. 197

References .................................................................................................................... 201
Appendix 1 Australian Morbidity and Treatment Survey instruments...... 219

Appendix 2 The management of chronic conditions in general practice
protocols and instruments ................................................................. 221

Appendix 3 ............................................................................................ 223

Appendix 4 ............................................................................................ 225

Glossary ............................................................................................... 227

Boxes

Box 1.1 Experiences, Needs And Problems In Relation To Chronic Conditions And
General Practice Care (Members Of Four Self-Help Groups: Diabetes, Epilepsy,
Cancer, Asthma)................................................................. 3

Box 1.2 Ideas About Chronic Disease And Illness Management In General Practice (GP
Colleagues)........................................................................... 4

Box 1.3 Ideas About Chronic Disease And Illness Management In General Practice
Clinical Or Biomedical Skills......................................................... 5

Box 2.1 The biopsychosocial framework for chronic illness ........................................ 16

Box 5.1 Examples of chronic conditions from ICPC listings from Dutch GP continuous
morbidity recording ........................................................................... 74

Box 7.1 Sources of quantitative data for Chapters 7 and 9........................................ 91

Box 7.2 Variables and conceptual model for the Survey of GP attenders on Repeat
Prescriptions used in quantitative analyses in Chapters 7 and 9...................... 93

Box 8.1 GP and their attenders - Participants in the study of ‘Experiences of disease,
ilness and treatment’ analysed in Chapters 8, 10 and 12.............................. 109

Box 8.2 The data-set of the study of ‘Experiences of disease, illness and treatment’ .... 110

Box 9.1 Variables entered into hierarchical models of Dissatisfaction .................... 135

Box 13.1 A suggested schema for improved implementation of chronic illness care in
Australian general practice .................................................................. 193

Box 13.2 A model of general practice social support in chronic illness consultations...... 197

Figures

Figure 5.1 Age-sex distribution encounters with at least one chronic disease recorded as a
percentage of all encounters in children under 15 years in the Australian
Morbidity and Treatment Survey......................................................... 55

Figure 5.2 Psychosocial interventions in chronic physical and psychological consultations as
by general practitioners in Australian Morbidity and Treatment Survey............... 71

Figure 6.1 The proportion of ‘longer’ (than ‘standard’) Medicare GP services, bulk-billed
and privately billed in Australia and the ACT 1984/5-1991/2.......................... 83

Figure 7.1 SF-36 Scores of 294 general practice attenders........................................ 102

Figure 8.1 General practice participants in interviews as reported in Chapters 8, 10 &11..... 108

Figure 9.3 Schematic representations of important factors associated with Dissatisfaction 142

Figure 13.1 Clinical frameworks. A model of theoretical constructs underpinning chronic
disease and illness care ...................................................................... 196

Figure 13.2 A model of chronic disease and illness care in general practice
consultations .............................................................................. 198
Tables

Table 5.1 The most common chronic diseases diagnosed in encounters of children under 15 years at which one chronic disease had been recorded........................................56
Table 5.2 Most common reasons for encounter recorded by general practitioners in encounters with a chronic disease diagnosis in children under 15........................................56
Table 5.3 Encounters for children under 15 years, at which a chronic disease and psychosocial intervention were recorded........................................................................57
Table 5.4 Logistic regression with random effects model of factors best explaining the differences between ‘serious’ chronic disease encounters and all other encounters including minor chronic illness childhood encounters.......................................58
Table 5.5 Logistic regression model with random effects of factors best predicting the reporting of psychosocial care in all childhood encounters......................................59
Table 5.6 Most common chronic physical and psychological diagnoses in chronic physical condition and encounters with a psychological diagnosis........................................61
Table 5.7 Most common reasons for encounter in chronic physical condition encounters and encounters with a psychological diagnosis in adults................................................62
Table 5.8 The characteristics of chronic physical, psychological and co-morbid encounters in children under 15 years, at which a chronic disease and psychosocial intervention were recorded ..............................................................63
Table 5.9 Logistic regression models of factors best explaining the characteristics of chronic physical condition encounters and psychological encounters and their overlap in adult consultations................................................................................................64
Table 5.10 Logistic regression model of GP and consultation factors best explaining the characteristics of chronic physical condition encounters in Australian general practice..................................................................................................................68
Table 6.1 Logistic regression model of billing for ‘longer’ vs ‘standard’ GP consultations. The Australian Morbidity and Treatment Survey 1990-91 ....................................................84
Table 6.2 Logistic regression model of billing for ‘longer’ vs ‘standard’ GP consultations. The ACT Record Linkage Study (1988-92). ........................................................................84
Table 7.1 Five most common conditions reported by 294 patients on repeat prescriptions, who were consecutive attenders of 23 GPs and a national cross-sectional sample of 467 GPs .........................................................................................................................98
Table 7.2 Self-reported socio-demographic, health care and health status profiles of 294 consecutive general practice attenders on long-term medication located in NSW, ACT and Melbourne and 42 self-help group members.................................................100
Table 7.3 Mean SF-36 scores reported by male and female patients of different ages of 294 general practice attenders and 42 self-help group members.........................................................103
Table 7.4 SF-36 scores in 294 general practice attenders on repeat prescriptions compared with 555 members of an ACT population sample...........................................................................104
Table 9.1 Spearman correlation coefficients of six SF-36 domains with Met Need, Felt Need and Illness Impact Scales in 294 general practice attenders.........................................................136
Table 9.2 Hierarchical loglinear models of significant interactions among Dissatisfaction, Felt need (for clinical care, supportive relationship and supportive care structure) Illness Impact Scale and SF-36 scales in 294 general practice attenders..................................................................................................................138
Tables 9.3-9.6 Hierarchical models of significant interactions among Dissatisfaction, Felt Need (for clinical care, supportive relationship and supportive care structure) with self-reported GP and other service use profiles and personal characteristics in 294 general practice attenders .................................................................................................................139
Table 9.7 Logistic regression model of best explanatory variables of greater Dissatisfaction with general practitioner care in 294 general practice attenders.................................................140
Part 1

The nature of chronic illness and disease

Theoretical frameworks
Chapter 1

Approaching the study of chronic disease and illness in Australian general practice

An exploration of problems and issues through focus groups and an outline of the approach of this thesis

Abstract

Understanding difficult personal experiences of disease and illness as a patient and general practitioner motivated this study. I began with a conviction that chronic care was problematic and could be improved with greater understanding. I conducted a preliminary literature review that indicated that care of chronic conditions covers a broad range of topics with a vast number of publications. Disease-based management dominates the medical literature, while psychosocial and behavioural aspects of illness and care are described to be equally or more important for adequate self-management in the literature. I approached chronic disease self-help group members and general practitioner colleagues to help me clarify what questions I needed to ask about relevant issues, in order to achieve my aims. Self-help group members reported that many general practitioners lacked clinical and interpersonal skills needed for chronic care and that finding the ‘right’ general practitioner was difficult, but important. The ‘right’ general practitioner provided integrated care across their range of physical, psychological and social needs and did not reject them if such care became difficult. General practitioners reported that there was insufficient time in consultations, inadequate knowledge about biomedical disease or training for psychosocial management and not enough support in the health-care system for adequate chronic care. In order to understand this complex care, I identified the need to define and understand the nature of chronic disease and illness at the level of the afflicted individual, the general practitioner, and the system of general practice.

Introduction

I first came to this topic because of the almost fatal consequences of the medical mismanagement of my health care. I experienced the effects of lack of time and effort taken to understand my condition by one group of medical practitioners, the exemplary care by another group, and (perceived) lack of support from general practitioners, to serious illness. As a practising general practitioner, in much better health, I returned to this topic, because I found that chronic care was difficult and time-consuming with intense personal demands. This forced me to question the processes and directions of my efforts. In order to understand the nature of these difficulties, I began a preliminary literature review in conjunction with informal discussions with patients, academics from a range of disciplines, and general practitioner colleagues. The review located a vast literature (32,905 articles on the Medline database from 1990–5/1997) on certain high-profile specific diseases such as: diabetes, asthma, hypertension, rheumatoid arthritis and schizophrenia, covering medical treatment, clinico-pathological and biological, and
psychosocial issues. Biomedical and therapeutic issues dominated this literature, which did not help sort out the difficult nature of managing chronic disease. Other literature dealt with the psychology and behavioural aspects of special disease types, for example diabetes, but again, did not reflect issues such as the appropriate use of my time in chronic care when in practice. Taking another perspective, literature on stress, coping resource and coping strategies viewed chronic illness as a stressor and sought to quantify theoretical concepts to advance knowledge through scientific means (Medline search 1990–5/97 found 403 articles). Another rapidly expanding literature which emerged was the literature on measurement; the use of instruments of functional status, global and specific health outcomes, to evaluate health outcomes. A distinct sociological literature on social theories of disease and illness vigorously critique the medical model of care in chronic illness. This literature highlighted the distinction between disease classified according to a clinicopathological framework and illness, the personal psychological, social and physical experiences of poor health, and consequent suffering. Therefore, I identified a broad range of disciplines pertaining to the study of chronic illness and disease management that covered biomedical, psychological, interactional and sociological theories. Economic theories were also involved because chronic disease and illness was expensive for the individual and society. It became clear that as a general practitioner, I did not have clear models of what chronic illness was, nor of what my processes in the consultation involved, particularly in the psychosocial domain, nor did the literature readily provide such models. Evidence was fragmented across many domains. I identified a ‘gap’ in the research literature about generalist care of chronic disease and illness.

Exploratory focus groups

In order to clarify my research questions, generate hypotheses, and ‘validate’ my personal sense of the difficulty and ‘problematic nature’ of chronic illness care, I conducted nine focus groups in April and May 1991. Self-help groups were chosen as readily identifiable people with personal experience of chronic disease and likely to have considerable experience of general practice care. I approached four mainstream chronic physical disease self-help groups who agreed to invite members to a special meeting to discuss chronic illness care in general practice. Thirty self-help group members from the Epilepsy Association of the ACT, the ACT Cancer Society, the Asthma Association of the ACT and the non-insulin dependent diabetes self-help group of Diabetes Australia, Canberra, participated in four focussed discussions which were audio-taped. The self-help group members, who attended the meetings, described themselves as core members who actively ran their organisation, or as those who were in a crisis of diagnosis, treatment, experiencing a threat to life, function, or personal problems. The majority of members, in comparison, were described by the focus group
participants as those who received the newsletter, more likely to have stable conditions, and did not participate in the active processes of the group.

A parallel series of five focussed discussions of a group that varied in number from five to nine general practitioner colleagues explored the domains and problems of chronic disease and illness in general practice. The general practitioners had all worked in community health centres, private practices, and had experienced working in a multi-disciplinary team. They were of mixed age (30–55 year age range) and gender (60 per cent female) and all had worked in private practices of different types at various stages of their general practice careers.

BOX 1.1:
EXPERIENCES, NEEDS AND PROBLEMS IN RELATION TO CHRONIC CONDITIONS AND GENERAL PRACTICE CARE (members of four self-help groups: diabetes, epilepsy, cancer, asthma)
NEEDS OF PEOPLE WITH IN RELATIONSHIP TO GP AND OTHER CARE
- Living with protracted uncertainty or the inevitability of decline required hope and understanding.
- Living with pain or disability or diminished social role was difficult and required empathy and encouragement.
- An awareness of the personal and social impact of illness was needed from family, friends and health-care providers.
- All wanted the 'right GP' to provide whole-person care—characteristics of the 'right GP' included: supportive, interested, helpful in clinical and practical way, good diagnostic skills with up-to-date knowledge of when to refer, investigate and treat.
- Appropriate access and availability to GPs, specialists and other professional care when needed.
- Good communication between providers.
- Continuity of care to have condition, treatment needs known and met by someone they could trust.

PROBLEMS
- Difficulty finding the 'right GP' to provide whole-person care who was prepared to commit to long-term personal chronic illness care.
- GPs often lacked skills in diagnosis, willingness or ability to provide adequate explanation and information, often rejected patients when they were threatened by the incompleteness of their own skills or medical knowledge.
- The frequent inability of the GP to know enough about specific conditions, but common inability of the specialist to know the whole person.
- A lack of time given to explanation and information about medical, psychosocial and practical issues related to disease management.
- The dynamics of a long-term doctor-patient relationship usually lead to support or friendship, but could lead to complacency or oversight.
- Although self-help groups filled an important gap, understanding of the individual, their chronic illness and circumstances by professionals was often lacking.

Although neither the general practitioners nor the self-help group members, were necessarily a representative sample, they were considered likely to be able to identify valid content areas for the research. Content analysis was carried out and the range of themes identified and described. The general practitioner discussions were thematically analysed during and after the meetings. Results were fed back at subsequent meetings. The self-help group focussed discussions were audiotaped, transcribed and common themes identified. Common themes were aggregated into broad issues or categories. Important and difficult issues raised by the self-help groups members are described in Box 1.1. The general practitioners’ outline of problems from their own perspective and their perceptions of problems for their patients is reported in Box 1.2. Frequently
described themes, identified in both general practitioner and self-help discourses, were developed into study questions and hypotheses.

BOX 1.2: IDEAS ABOUT CHRONIC DISEASE AND ILLNESS MANAGEMENT IN GENERAL PRACTICE (GP colleagues)

SYSTEM FACTORS
- Lack of time for adequate consultation with patients, to listen, to explain, to empathise.
- Lack of time for adequate liaison with specialists/primary health-care team/family.
- Financial disincentive linked to lack of time—lack ‘adequate’ remuneration, fears of ‘overservicing’, medical skill, emotional and time demands are greater, generating longer consultations with only the same payment as for simple quick acute problems.
- Lack of training in the interpersonal skills needed to deal with the types of emotional social problems faced by complex chronic patients.
- Personal factors—stress arose from emotional involvement.
- Lack of debriefing, lack of support, lack of “supervision”/case discussion in ongoing complex management situations.
- Lack of a “panacea” or biomedical cure for GPs to offer, inevitability of deterioration.
- Practice management and information systems needed—such as repeat prescribing, disease registers and age-sex/at risk registers and recall systems were needed.

STRUCTURAL FACTORS IN NETWORK OF CARE
- Fragmentation between/with multiple specialists.
- Fragmentation between/with different other primary health-care providers.
- Conflicting advice/lack of integration of advice and services.
- GP advice/services dominated by technical considerations because of under representation in clinical thinking of personal, family social life type issues.
- Insufficient DEVELOPMENT of the POTENTIAL of the GP role in the medical management of chronic conditions by GPs and others in the medical system and in the response to population/community needs.

PATIENT FACTORS
- Lack of power in the system—often ill, older, weaker less able to determine that treatment is suitable for their wider needs.
- Lack of knowledge about what is ‘good’ treatment, about their treatment and their condition, lack of knowledge about services.
- The expert patient—more knowledgable about disease than most professionals; usual doctor-patient competence gap was over-turned—sometimes this was a good thing, other times this was a problem.
- Consumer sovereignty—patients may determine their own pathway through their disease outside traditional medical wisdom; which meant that GPs who were managing them were not adhering to ‘best practice’.

Overall, the discussions of general practitioners and self-help group members reflected concern that the general health-care system, including general practice, was not meeting the needs of those with chronic ill-health. At an individual level, self-help group members identified exemplary experiences of general practitioner care (often their own general practice care after much searching for the ‘right’ general practice). However, at a broader level, they identified substantial deficiencies in the way many general practitioners worked. The lack of skills in diagnosis, the inability or unwillingness to give appropriate information, personal rejection when general practitioners were confronted by the incompleteness of their own skills, or the limits of medical knowledge, as well as, inadequate responsiveness to the personal and social impact of illness, were major themes. The lack of time in consultations was frequently mentioned by both groups.
General practitioner colleagues’ views of the difficulties of the interpersonal care for those with chronic illness and disease resonated with my concerns. Over time, it was often only the doctor-patient relationship that could support people when biomedicine had failed. However, this was stressful. Inadequate remuneration for appropriate consultation time and an apparent lack of bureaucratic understanding of the role of the general practitioner detracted from quality of care.

Technical, relationship and communication issues at the clinical level, and the bureaucracy and economic constraints at system level, were dominant themes. General practitioner colleagues indicated both an incomplete understanding of chronic care and the difficult and demanding nature of such care. Self-help groups members perceived that general practice care was often ineffective in biomedical, psychological and social domains, while some general practitioners provided exemplary care. Everyday approaches were pragmatic rather than based upon any articulated model of care, yet the difficulty of dealing with the burden often weighed heavily upon those involved. The emerging complexity of the management of patients with chronic-care needs resonated with my personal experiences as a general practitioner and as someone who had experienced serious personal illness.

BOX 1.3:
IDEAS ABOUT CHRONIC DISEASE AND ILLNESS MANAGEMENT IN GENERAL PRACTICE

CLINICAL OR BIOMEDICAL SKILLS
Patient perspective: need for sufficient or better GP disease-specific knowledge to adequately diagnose, investigate and refer; but more holistic approaches by specialists;

GP perspective: need for and access to better biomedical knowledge; yet excessive emphasis on technical care.

PERSONAL (PSYCHOSOCIAL) NEEDS AND THE DOCTOR-PATIENT RELATIONSHIP
Patient perspective: need recognition of personal and social impact of illness; non-rejection by GP in face of inadequacies of interpersonal skills or medical knowledge; continuity that does not produce oversight or complacency; provision of sustaining hope, understanding, encouragement and practical assessment and factors—difficulty in finding the ‘right’ GP who was committed, caring and technically competent.

GP perspective: the doctor-patient relationship—need for and access to training, debriefing, support and case-management in relation to complex interpersonal skills; need recognition that such care is often stressful and demanding;

health factors—generally lack of power and knowledge when confronted by complex care needs, but sometimes perception of superior knowledge not needing GP or rejection of conventional wisdom not following ‘best practice’.

HEALTH SYSTEM
Patient perspective: adequate consultation time often not available but needed to provide information explanation, empathy and liaison with family and other health-care providers; need for adequate access, availability when needed to GP and other services, and care coordination.

GP perspective: adequate consultation time often not available but needed to provide information explanation, empathy and liaison with family and other health-care providers;

inadequate remuneration with disincentives to provide complex chronic care;

health system organisation produced fragmentation of, gaps and even conflict in, management with multiple providers; need for adequate access, availability when needed of health and social services, and care coordination.

The unhappiness revealed in the self-help groups and general practitioner groups about current models and implementation of care clearly warranted further study, and a view of this issue that integrated the biomedical and the psychosocial. Remuneration and the structure of health-care systems were seen by both groups as unsupportive. The issues
identified in the focus groups were categorised further into three common themes shown in Box 1.3.

**Formulation of the thesis approach**

On analysis of these experiences, several important issues emerged. First, there was a need to understand what was meant by chronicity, illness and disease; the similarities, differences and how they can be constructed. Because they are the key stakeholder, the person with the condition should be the dominant focus of this understanding. However, the general practitioner is also a primary stakeholder: it is the general practitioner’s particular perspective and contribution to each patient that collectively contributes to the quality of general practice care.

Second, because general practitioners are involved in generalist care of people with a wide range of chronic conditions, there is a need to study *generic* chronic disease and illness. The usual approach is to study a single disease type as a ‘tracer’ for other chronic diseases (Kessner, Kalk and Singer 1973). Here there is less interest in the commonalities or the generic nature of different chronic conditions than in specific issues, often biomedical, related to idiosyncrasies of particular conditions (Stein and Jessop 1989; Perrin et al. 1993; Jessop and Stein 1994). The trend to the study of single diseases necessarily means that the care of chronic illness or the complex patient, with many problems, who consumes considerable health-care resources—general practitioner and primary care, specialist, hospital and pharmaceutical—was not well-researched and there is a gap in the literature. On a crude level, in a search of the Medline database of the years 1990 to mid 1997, in relation to general practice, there were 101 papers on chronic disease, but only 17 on chronic illness (with 32,905 on chronic disease and 807 on chronic illness overall). The typical disease-centred approach viewed the presence of co-morbidity (other conditions that confound outcomes of disease-based management) as problematic both to researchers and clinicians (Kessner, Kalk and Singer 1973). To take the example of diabetes, possible co-morbidities could include loneliness, poverty, ischaemic heart disease, hypertension, asthma, gout, and would complicate blood-sugar control. However, together these conditions would produce a certain profile of illness and need for self and other care. A range of very different patterns of diagnoses and conditions (rare or common) could also produce a similar pattern of illness and need for care. Therefore, I decided to look for indicators of generic chronic disease such as repeat prescriptions, condition lists and general health status measures that reflected commonalities across typical chronic presentations in general practice and did not force artificial distinctions between co-morbidity and morbidity.
Third, with a perceived encroachment on the generalist role of the general practitioner by specialists, paramedical staff and others, it appeared important not only to describe the complexity and depth of the work of the general practitioner, but more clearly to define and understand the ‘specialised’ processes involved. It is important, thus, not only to review the management of the chronic patient, but to demonstrate aspects of the nature of general practice, and to work to elucidate further the nature of generalism.

Fourth, the care of chronic illness needed to be considered at three levels:

- individual experiences of patients and general practitioners;
- commonalities in the needs of chronic illness patients; and
- how general practice deals with them at the system level.

Finally, general practice is an emerging academic discipline. It makes use of many disciplines. General practice needs to develop cross or transdisciplinary links to evolve its own essential theories. Processes which integrate theory, evidence and practice from a general practice perspective, require exploration and development.

At this point, I encountered a paper by Rosenfield (1992) on transdisciplinary processes in health services research. It became clear that as a general practitioner, I was engaged in transdisciplinary processes in my everyday clinical practice—triangulating biomedical care with psychosocial and counselling models of care, administration or health promotion. For a general practitioner researcher, the parallels in academic practice were inescapable. As the real question behind my thesis began to emerge: ‘what are appropriate biopsychosocial models of care for chronic disease and illness in general practice at the clinical and structural levels?’ or ‘how to integrate insights from biomedical and psychosocial care literature’, it began to become clear that to approach this problem, integrated transdisciplinary research methodologies were needed (Martin and Peterson 1997). In order to address the complex needs for synthesis of many disciplinary approaches that differently reflect the nature of primary care, it is necessary to reflect briefly on the nature of research. What is it and what are the essential nature of its structures and processes? What are the main types of inquiry? How do researchers group themselves—based upon disciplines and paradigms, theories and movements, such as epidemiology, essentialist post-structuralist etc.? How do research processes evolve? Can diverse disciplinary perspectives be synthesised?

**Research questions for the thesis**

I identified the following as research questions:
• What is the nature of chronic illness and chronic disease as general phenomena and as seen in general practice?

• What characteristics of generalist medical care and the long-term doctor-patient relationship are likely to influence the outcomes of chronic illness?

• What is the emphasis of contemporary general practice care?

• Is the care of chronic physical disease associated with a doctor-patient relationship providing continuity, personal support, commitment and practical help or is it focussed upon disease so that the illness needs of people are being ignored?

• Does the health-care system support chronic illness care in general practice?

• Is adequate consultation time provided to support chronic illness care—(time for information, explanation, empathy, encouragement and liaison with family and other providers)?

• What is the nature of physical and psychosocial co-morbidity (chronic illness) that accompanies chronic physical disease seen in general practice? What do people with chronic disease and illness want and need from their general practitioner?

• How do people who attend general practitioners for chronic physical disease care, construct chronic illness, the doctor-patient relationship and support needs?

• How do general practitioners construct chronic illness care to accompany chronic disease management?

• Do general practitioners and patients perceive problems in the current system in relation to health and social service provision?

• What are appropriate nomenclature, frameworks and categorisation for evidence and practice across a broad spectrum of disciplines?

• What does chronic illness tell us about the intellectual discipline of general practice? Is there a case for transdisciplinary models of theory, evidence and practice? What sorts of models of chronic illness care are appropriate and how may these be developed?

Aims, objectives and methodological approaches

In response to these questions, I produced a broad overview of the complexity of chronic illness care and a synthesis of guiding principles. I argue that the biopsychosocial nature of chronic illness and the subjective nature of general practice
care cannot be reduced to ‘facts’. Single disciplines can contribute to the knowledge base in this area, but this will present only an incomplete picture. Transdisciplinary approaches are needed, that by their nature integrate other approaches including philosophical, sociological, clinicopathological and qualitative with more quantitative approaches (Rosenfield 1992; Malterud 1995; Stange 1996). In order to accommodate the historical traditions of knowledge creation within different disciplines, particularly those based upon logical argument versus those based upon statistical techniques, research approaches need to develop linkages and processes of synthesis. Such approaches should not distort disciplinary paradigms, without an understanding of the assumptions and logic of knowledge creation (Martin and Peterson 1997). Therefore, each element of analysis of the thesis aims to conform to the rules of the discipline in which it is primarily located. However, in order to achieve synthesis into an overview and principles, the final analysis will be at an order of abstraction that is beyond disciplinary constraints, but deferring to their logical constraints.

The emerging discipline of general practice—intellectual and scientific

Because general practice care sits at the interface of biomedical and personal psychosocial care, it needs to be informed by ‘evidence’ and knowledge about both modalities (Rosser and Maguire 1982). Traditionally, medical practice has relegated psychosocial aspects of care to an ‘art’ not requiring evidence. Otherwise, general practitioners typically view these aspects to be informed by ‘soft’ evidence from social science that has been judged not to conform to the methodological ‘rigour’ of biomedical evidence. Conversely, social scientists have observed deficiencies in biomedical approaches based upon lack of intellectual rigour and flawed assumptions. In 1959, C P Snow first published a book detailing the ‘polarisation of the two cultures’—those based upon argument and intellectual logic, and those based upon empirical science. He argued for a third culture that would bridge the gap (Snow 1993). The intellectual discipline of general practice has a wonderful opportunity to bridge these two cultures. It has an added challenge to translate these linkages to inform the actions of clinical practitioners.
Chapter 2

Defining chronic disease and illness

‘Naming and framing’: nomenclature and frameworks in chronic disease and illness

All systems of definition and classification are perceptual, artificial and arbitrary. Whose definitions prevail at any given time and place is a matter of politics, persuasion and preference (Quinn Patton, 1986).

Abstract

I explore definitions, dialogues and meanings around long-term physical health problems with a medical diagnosis. Chronicity is a value-laden term implying incurability, difficulty in living, dependency and cost according to a perspective. Disease refers to diagnoses categorised in the biomedical system according to aetiology, pathophysiology, signs and symptoms, treatment. Conditions, syndromes and disorders are similarly categorised, but are less well-defined in pathophysiological or aetiological terms. Diseases (or other categories) that are chronic, are of long duration, but may or may not be symptomatic.

Biomedical classification systems do not typically include seriousness, severity or similar terms that may qualify disease in a range of domains including prognosis, need for intervention, and impact. Other classification systems, in contrast, focus upon disability, self-assessed health and quality-of-life measures. The biomedical system has implied clinical pathways and algorithms for action associated with diagnoses. Other classifications do not have such frameworks that are applicable to primary medical care and hence are primarily descriptive. Illness refers to the subjective nature of bodily disturbance and how people live and cope with the disruption it can bring. Defining chronic illness in an operational clinical framework is difficult, yet important, because of its incurable nature, long duration, impact on the afflicted, their families and costly service needs.

Chronic illness and medical and social responses to it, are best understood through social constructivist approaches that straddle empirical, theoretical interpretation and explanatory approaches. Nomenclature and framework structure the responses to chronic illness of the ill themselves, their medical providers and society. Current medical categorisation remains predominantly biomedical and disease-focused. Although a wide range of descriptive classifications focus upon quality of life and broader approaches to health, these do not necessarily provide frameworks for chronic illness care.

Defining terminology

Chronicity

Chronicity is a construct related to the duration and nature of long-term health problems. Perspectives on chronicity range from those of the afflicted individual, their close network, medical and social researchers and care providers, policymakers and funders. The terminology or labelling system that is used varies with the philosophy or discipline of different stakeholders (Bury 1982; Charmaz 1991). Sociological researchers study
chronicity at three levels: the individual (phenomenology), the social (sociology of roles, norms etc.) and societal (political economy of health and illness) (Turner and Samson 1996). More applied social and public health researchers emphasise measurement of the physical, the social and mental function, quality of life, aetiology and socio-economic factors, including behavioural and occupational circumstances, that predispose to chronic poor health (Bowling 1990; National Health-Strategy Group 1992; Mathers 1993; Bowling 1995). Those in government and health-care funding areas emphasise politically expedient and/or cost-effective outcomes of financial investment in programs and services (Strauss and Corbin 1988). The nomenclature and frameworks used define not only the boundaries and conceptual space occupied, but shape and are shaped by individual, social, economic and political responses to chronicity (Brown 1995).

The key feature of chronicity is persistence: there is no known medical cure (Rothenberg and Koplan 1990). Duration and impact are two consistent dimensions that describe chronicity across stakeholders (Stein and Jessop 1985). Definitions of duration and impact generally include: current or expected length of problem, diagnostic category, disease impact on quality of life, functional status and prognosis and the impact on the primary network (Cadman et al. 1986; Knottnerus, Metsemakers and Limonard 1992; Westbom 1992; Jessop and Stein 1994). In a classic definition pertaining to medical or health care, Mayo (1956) described chronic illness as:

‘impairments or deviations from normal which have one or more of the following characteristics: are permanent; leave residual disability; are caused by non-reversible pathological alteration; requiring specialist training of the patient for rehabilitation; and may be expected to require a long period of supervision, observation and care.’ (Mayo 1956:8).

In another epidemiological and biomedical view, chronic diseases are:

long in duration—often with a long latency period and a protracted clinical course; of uncertain aetiology; with no definite cure... The clinical notion of chronicity is reflected in the epidemiological characteristics of most chronic diseases: gradual changes over time, asynchronous evolution and heterogeneity in population susceptibility (Rothenberg and Koplan 1990:267).

The World Organisation of Family Doctors (WONCA) defines chronicity as a health problem or an episode of care lasting six months or longer and illness as a subjective state of not feeling well (Bentzen et al. 1995).

The commonest approach to a practical epidemiological definition of chronicity is the use of ‘lists’ of diseases, conditions and disorders recognised as being long-term in most
instances, such as diabetes, asthma, cerebral palsy, or schizophrenia (Perrin et al. 1993). The World Health Organization has used such ‘condition lists’ to gather information on the prevalence of chronic health problems (WHO 1982).

Likewise, in a more individual-centred approach, Curtin and Lubkin (1986) define chronic illness as:

the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability (Curtin and Lubkin 1986:6).

Subjective and unpleasant experiences accompanying chronic conditions involve the total human environment, including financial, sexual, legal, marital or psychological states (Strauss and Glaser 1975). The ill, and their family, may have major threats to their identities, as well as requiring assistance with physical matters such as transportation and doing housework (Strauss and Corbin 1988).

**Disease, illness, sickness and condition**

Depending upon a perspective, the terms *chronic disease, condition and illness* are either interchangeable, or convey different meanings. Most authors make philosophical distinctions between illness and disease. *Disease* strictly relates to a diagnosis based on a biomedical diagnostic classification system (Helman 1984; Stein and Jessop 1989; National Coding Centre 1995). Disease is the result of physiological or psychological dysfunction, a ‘biological dysfunction’ that is construed on the ‘basis of well-known pathological, or pathophysiological processes, or with a known aetiology’ (Bentzen et al. 1995:349). *Syndrome* is a presumed biological dysfunction of which the knowledge of causative pathological or pathophysiological processes is not accepted as conclusive (Bentzen et al. 1995:349). *Sickness* is the social role assumed or assigned during ill-health (Bentzen et al. 1995:349). *Illness* definitions vary from ‘the subjective state of the person, who is aware of having a health problem and not feeling well’ (Bentzen et al. 1995:349) to the presence of unpleasant bodily sensations, that people perceive to interfere with their ability to function in a manner acceptable to themselves and the group of which they are a part. *Condition and disorder* are general terms referring to either disease, symptoms or the state of a person’s health from any perspective (Bentzen et al. 1995:347). Because they are less value-laden terms (that is, linked to biomedical classification or other systems), condition and or disorder, are often preferred in primary care. However, they may also lack specificity (Perrin et al. 1993).
Qualifications

Severity, another term, describes a threshold for classifying disease or conditions into different levels. Severity is based upon results of laboratory tests, the degree of pathology of an involved organ, or the implications and impact. In asthma, for example, mild could mean requiring occasional bronchodilators as opposed to being life-threatening, that meant requiring regular emergency admissions. Severity, according to its definition, requires additional information beyond diagnostic classification. Severity can be classified in medical, personal or multi-dimensional terms (Jessop and Stein 1985) or reduced to a visual analogue scale (Parkerson, Broadhead and Tse 1993).

'Seriousness' is a term used to group diagnoses according to the involved bodily organs and likely type of impact; for example lungs or brain versus skin (Weiland, Pless and Roghmann 1992). The other qualification of chronicity is the stability or variability of the disease process and the accompanying illness. This is emphasised in the chronic illness literature with the trajectory model of Strauss and Corbin (1988). Disease course is emphasised in medical textbooks such as Harrison (1993) but not generally included in biomedical classification systems such as ICD-9-CM and ICPC.

Classification of actions

Medicine is an 'action discipline' utilising applied knowledge (Querido, Es and Mandema 1994). The WONCA classification committee (Bentzen et al. 1995:346) defined disease as 'a concept of reality and can therefore exist without a physician's judgement' as opposed to illness that is 'subjective'. What is illness? Wherein does illness exist in biomedical classification systems such as ICD-9-CM and ICPC? Such systems classify 'actions' of medical care in relation to objective diagnosis, for example the process of making a diagnosis, suturing and other procedures or counselling in response to a disease, syndrome or a condition. The actions related to disease are specific, particularly if procedural, and are recognised and financially rewarded in Australia (HIC 1997). Those actions, related to illness, (which do not generally appear in classification systems) are non-specific or relegated to 'non-specific' non-diagnosis related management (Lamberts and Woods 1987; National Coding Centre 1995). They are sometimes labelled the 'art of medicine' (Blois 1988). Systems used in primary health care include codes for 'non-specific' care or non-disease-based care domains. Yet by framing these areas in such a way, they become less important in the consultation and care processes. The notion of non-specific care is also difficult for coders to code, and for general practitioners to use in their assessment of the complexity of the consultation content. Failure to develop theory and practice in this area may account for its unaccountable 'work-value' in Medical Benefits schedules (Britt, Meza and Del Mar 1996; Deeble 1996; Harris et al. 1996). Yet the skills required here, may well be far more complex and important to community health, than the skills required for highly remunerated activities like gastroscopy or tonsillectomy.
Defining and framing illness—non-disease based systems

The World Health Organization (1945) definition of health as a ‘state of complete physical, mental and social well-being, not merely the absence of disease and infirmity’, endorsed a shift away from a primarily disease-based model to a health and wellness-based model in health care (WHO 1982). Illness, therefore, must be some degree of shift from an optimum state of health. Definitions of deviations from an optimum state of health include domains of an individual’s experience and functional ability. The World Health Organization also produced an International Classification of Impairments, Disabilities and Handicaps (ICIDH). Disability overlaps with chronic illness and disease conceptualisation with the implication of chronicity, severity, stability and impact upon life experience and functioning in multiple domains. In the context of the health experience ‘impairment’ represents any loss or abnormality of physiological, psychological or anatomical structure or function. ‘Disability’ represents any resultant restriction or lack of ability to perform an activity, while ‘handicap’ represents any resultant limitation or prevention of fulfilment of a ‘normal’ role for the individual (Madden et al. 1996).

The World Health Organization has undertaken to revise its 1980 ICIDH. This is in fulfilment of WHO’s constitutional mandate and in response to a call to update the ICIDH made by several experts. The roles attributed to the concepts of impairments, disabilities and handicaps have expanded in number and in reach over the years. In addition to clinical and social applications, they carry key legal, ethical and economic dimensions. In a nonspecific context, the word disability, owning to its multi-faceted nature, refers to all the consequences of diseases globally (that is, impairments, disabilities and handicaps), and is emerging as a leading public health concept for classification and intervention.

The revision of the ICIDH requires a community effort on the part of its participants. It is essential that representatives of relevant WHO Programmes, Member States, United Nations agencies, non-government organisations (NGOs), patients’ associations and the medical industry take part in the revision process. Since July 1994, an initiative to examine the mental health aspects of the ICIDH has been underway in the Division of Mental Health and Substance Abuse Prevention. In view of its background, expertise, and network, developed as a result of this initiative, WHO has conferred the mandate to coordinate the ICIDH revision to this Division.

Currently, the 1980 (and 1993) ICIDH classifications are widely accepted in special disability services, rehabilitation, compensation, pension or social welfare social care (Madden et al. 1996). Using the WHO global definitions of health, however, it is possible for people to be both ill and able or healthy and disabled. Disablement, by
definition, is neither illness nor disease, but maybe associated with either or both. Therefore, the classifications have not gained everyday currency in general practice as providing either management categories or assisting in the ‘actions’ of clinical care, in Australia, at least (Madden et al. 1996).

**Biopsychosocial approaches**

The wider the view of disease, the easier it is to recognise the significance of cultural, psychological and social factors. This is usually referred to as the biopsychosocial model of health and has been largely adopted by general practice educators (Engel 1980; McWhinney 1989). Other approaches that compete with or complement biomedical approaches are behavioural medicine, holistic medicine, psychoneuroimmunology and environmental medicine (Foss and Rothenberg 1987; Foss 1994).

The majority of this work has been based upon the biopsychosocial model, analysed by many writers and operationalised by Medalie and Zynanski (1992) amongst others (Engel 1980; McWhinney 1989). Box 2.1 describes Medalie and Zynanski’s model: the biomedical or physical or biological, the psychological and the social. A strict delineation of each component clearly is impossible as domains are representational and symbolic, being nominal rather than essential. Biopsychosocial theory predominates in contemporary general practice literature (McWhinney 1992; Stott 1993; Pendleton 1995). However, more recently, general practice has been increasingly influenced by evidence-based disease models perhaps in an endeavour to overcome its marginal status in biomedical hierarchies (McWhinney 1996).

The nature of the discipline of medicine has been subject to considerable debate, yet whether the biomedical classification system can be linked to a biopsychosocial framework and classification system is contentious (Foss and Rothenberg 1987; Foss 1994). Unless this occurs, problems and medical responses that are non-disease-, syndrome- or condition-based are labelled *non-specific* in the main biomedical paradigm (Britt, Meza and Del Mar 1996).

**Box 2.1: The biopsychosocial framework for chronic illness**

- Physical (for example, mobility, dexterity, strength, pain, appearance).
- Psychological (internal cognitive, emotional and affective processes).
- Social (an individual’s relationships with people, institutions and physical surroundings).

*Elements of the biopsychosocial model adapted from (Medalie and Zynanski 1992)*

*The biopsychosocial model is differently operationalised: whether bio refers only to observable physical functions or includes microscopic and macroscopic physiology and pathology as organised and understood by biomedical systems varies.*

16
A social psychological approach

Empirical approaches to biopsychosocial frameworks for chronic illness

Measuring health and illness

Efforts to define health, have been, and currently are, impeded by the lack of conceptual definitions of health capable of being translated into suitable operational definitions. (Bergner 1985). Many indices have been developed. These range from a relatively restricted range of physical functioning to those covering a broad range of physical, social and psychological function, together with health-related quality-of-life measures. Most have been developed using psychometric techniques for combining individual data elements into aggregate measures. Mental health assessment, social health assessment and health-risk appraisal have also been developed (Ware and Kleinman 1992). Ware’s (1994) theory uses an analogy of concentric circles to describe health and illness impact on life involving self, micro- and macro-environments. The instruments used to assess health and illness range from the Sickness Impact Profile, the Nottingham Health Profile to the increasingly dominant SF-36 instrument from the Medical Outcomes Trust. From 1990 to 1995 and 1997, 206 papers have been published describing use of the SF-36 instrument in health care and ‘outcomes’ studies. In the same period there have been 9,332 papers on health status and chronic disease with 29 on self-assessment of health or self-rated health. World Health Organization Quality of Life (WHOQOL) is a next generation effort in this endeavour (WHO 1995).

Quality of life: global measures

There has been a huge growth in the empirical research concerned with health-related quality-of-life research. In the years 1990 to May 1997, there were 13,693 references to health-related quality-of-life research on the Medline. A random review of the subject matter of these articles showed that a major component of these papers used quality-of-life domains that assume prolongation of life and restoration of functional capacities (Albrecht 1994). Traditionally, the three-dimensional biopsychosocial model is employed (Medalie and Zynanski 1992). However, a comprehensive gold standard for measuring quality of life or health in chronic illness does not exist (Olweny 1993). Because there is no evident point of cure, quality of life is an obvious means of assessing the quality of care provided. However, quality of life is subjective and relative. Olweny (1993) describes quality of life as a perception, a personal evaluative state of the current vis-a-vis the expected lifestyle. At any one time, this represents the functioning of an individual within their unique and time-variable milieu.

Other problems exist in this burgeoning system of classification of health and quality of life. In the biomedical system, theoretically speaking at least, a diagnosis implies biomedical knowledge, facts and theory and is the starting point for an algorithm or
clinical pathway for action. However, there has not been the same development in this field of assessment of quality of life or health status or function (Bowling and Brazier 1995). How do general practitioners, or other health professionals, improve self-rated health, and reduce mortality as poor self-rated health is an independent predictor of mortality? Physical, psychological, occupational therapies and rehabilitation may improve some outcomes in chronic illness, although as in many areas, there is a conspicuous lack of evidence. Such approaches have not yet become linked with, nor the models integral to, general practice care in Australia. Understanding social health has remained particularly elusive and social interventions have produced equivocal results (Thoits 1995). However, social models of health and illness are essential and this will be explored in greater detail below and in Chapters 3 and 12.

From a biomedical perspective, many of the studies linking behaviour to the immune system to health status and outcome, are inconclusive (see Greer 1991; Levenson and Bemis 1991; Redd, Silberfarb and Andersen 1991). Recently, a body of evidence is developing which is sufficient to stimulate further research. For example, it can be documented that levels of stress, marital status, social support and mental health are associated with observable physiological effects. It is still being debated whether these physiological changes cause traditional epidemiological outcomes such as mortality, morbidity and survival effects (Goodwin et al. 1987; Zonderman, Costa and McCrea 1989; Almada et al. 1991). The main problem is that conceptualisation and quantification of social health must address the ‘situatedness’ of individual experience in a biopsychosocial context, rather than merely appearing as ‘ill-defined variables’ in multivariate analyses (Lyons et al. 1992). However, there have been some promising findings even within the short duration of the systematic study of the topic. Several well-conducted studies showed improved survival in those who had enhanced social support interventions (Speigel et al. 1989; Stein and Jessop 1991). Another major study showed that health and survival beliefs affected mortality rates in ethnic Chinese Americans and American Jews (Phillips 1988; Phillips, Todd and Wagner 1993).

**Linear and complex systems**

In the field of general practice and primary care, health, health gains and outcomes of health care exhibit complex relationships. Non-linear relationships exist among outcomes, inputs and processes of care, making measurement and extrapolation to ‘quality’ difficult. In recent years, mathematicians have made considerable developments in the field of non-linear systems in diverse areas of life including social and health systems (Nicholis 1991; Kauffman 1995). Gould’s (1996) analysis of the anthropocentric constructions of the evolution of the species, for example, reveal our socially constructed biases in ‘hard science’. Such analyses place man at the pinnacle of evolution rather than the far more successful bacteria. Cultural factors clearly determine
the questions and interpretations of science. The reductionist scientific paradigm that has fashioned most of medicine's cherished notions about its 'hard scientific' basis is being very deeply challenged and questioned by many modern scientists (Kaufman 1995). Within biological systems, the complexity of patterns and interactions at a systems level are equally or more important than basic chemical reactions or molecular composition at an elemental level. Culture and technology are the 'cranes' that 'lift' human evolutionary development in the context of the diversity of human genetic and biological systems (Dennett 1995). Non-linear modelling of the complex cultural, technological and biological factors influencing health and the outcomes of care, will have an important bearing upon the understanding of patterns of interactions and outcomes of chronic care. The social construction of disease and illness experience depends on the situatedness of both the players and those observing the system.

**Linking models**

The diagnosis-specific or 'categorical' approach to chronic health problems promotes the concept of diseases as discrete entities. This discourages consideration of the common features of chronic conditions and understanding of generalist, generic or biopsychosocial approaches to their clinical care. Recently, however, 'non-categorical' or generic approaches, described in the paediatric primary-care literature, focus upon elements shared by the sufferer and their families across many conditions. They reflect the nature of chronicity: duration, the physical-mental continuum, the impact on quality of life, age-specific activities and financial, social or emotional burden imposed by the condition, irrespective of the medical diagnosis (Perrin et al. 1993). The 'patient-centred' model defines approaches, techniques and a style of communication that is accepted widely as likely to empower patients (McWhinney 1989). However, they and most biopsychosocial approaches, need further development to provide functional classifications of 'action' with a longitudinal perspective suitable for chronic illness.

Revisiting the biopsychosocial model, stress and social support theory link interpersonal and intrapersonal transactions with adaptation to noxious stimuli at biological and psychosocial levels. The structure, function and perceptions of support, it is argued, describe core actions and processes against which to view long-term general practice care for chronic conditions. Despite incomplete and sometimes controversial evidence, 'appropriate' support has been repeatedly shown to improve psychosocial and biomedical health outcomes in natural and clinical settings. What are appropriate interventions in clinical practice remains a major challenge (Austin et al. 1996). While relationships between coping, chronic illness and quality of life are well established, social health and support have been difficult to conceptualise. These are generally agreed to be important and measurement has produced less than satisfactory results in international studies. However, support constructs describe the 'action' and functions in
human interrelationships. In Chapter 12, support will be investigated further as an appropriate linking construct for classification and framing of general practice chronic illness care. Understanding the links between emotions, neuro-endocrine and immunological states and long-term health outcomes, needs further development. This should include examination of goals, and a 'deconstruction' of research paradigms and processes of knowledge creation that serve Western medicine. We require better constructions of what chronic illness is, the nature of the experiences of chronic illness and the actions required (in general practice care) to support those afflicted.

The experience of illness

Social theories, identify the pre-eminence of the lived experience of illness of individuals in the work of self-managing, from diagnosis through stability, instability to decline (Strauss and Corbin 1988). The representations of life, which the ill develop themselves, form the core of the 'work of managing' to keep their lives livable (Corbin and Strauss 1988; Strauss and Corbin 1988; Charmaz 1991). Illness has major consequences for social roles, family and organisational dynamics, and the functioning of society. This literature describes three biographies, the illness: the internal personal experience of unpleasant and disruptive bodily sensations, the sickness: the social role which society assigns, and the disease that is the medical diagnosis (Strauss and Glaser 1975; Engel 1980). People with different types of chronic conditions have different illness trajectories, however, biographical disruption, the loss of identity, uncertainty and loss of control of bodily function are universal (Bury 1982; Nijhof 1993). 'Losing one's way' with 'failing trust' of the body, particularly in the public world, is also universal although most applicable to stigmatising conditions such as Parkinsonism and epilepsy (Nijhof 1993).

Kleinman (1977), a leading anthropologist in the health arena, takes an almost nihilistic view of the diagnostic categories of Western medicine. He views illness, disease and sickness as completely culturally determined.

In the everyday interpretations of disease, people are mainly guided by discourses that are their own inner voice or the voices of those who are close to them, that help construct what is acceptable and competent for them in their environment of family and contemporary society. The health care that is being offered to the chronically ill is often not attuned to the problems they experience (Waltzkin, Britt and Williams 1994). It appears mainly directed to the medical interpretations of the problems, and less to the interpretations that people develop in the course of their life with the disease. In the research of Strauss and Glaser (1975), Bury (1982), Fitzpatrick and colleagues (1984), Corbin and Strauss (1988) and Nijhof (1993) the health care, which is offered, is not
orientated to peoples' subjective experiences and construction of meaning. The interpretations of professionals not only appear to be different from those of the chronically ill themselves, but also dominating over them. However, the medical profession has a powerful effect upon how people come to terms with illness. A number of contemporary sociologists including (Gerhardt 1989; Lupton 1993; Simon 1993; Woodward, Broom and Legge 1995) argue for more appropriate use of power and authority by the medical profession to provide constructive frameworks in which to work, rather than the medical dominance of the world view for the chronically ill. Processes of such constructive ‘medicalisation’ have been articulated by Woodward, Broom and Legge (1995). General practitioners who were unable to make a diagnosis in a biomedical framework, tended to dismiss people’s experiences of chronic illness and provided no framework in which to operate. A longitudinal study of people with chronic fatigue syndrome highlighted the enabling aspects of a coherent framework and emphasised the negative effects of having no explanation for their problems.

Identifying a framework for understanding chronic illness in general practice

Historically, there have been shifts and competing understandings of the nature of illness and disease and the social (including medical) responses they evoked. Functionalism, an early approach developed by Parsons (1951) and the role of the person who is ill, still has considerable relevance to modern medical practice (Armstrong 1989; Gerhardt 1989; Fox 1996). Such work has influenced modern medical sociology in its critique of the sick role, lay networks and medical power (Armstrong 1989; Gerhardt 1989; Turner 1996). Interactionism, and subsequently constructionism, while challenging functionalism, only partially displace it, adding to the sophistication of theory about how social roles and functions are constructed. Equally, post-modernism more recently, has provided major insights of the incorporation into the consciousness of the body or ‘embodiment’ of social values in medical care (Armstrong 1989; Turner 1996). However, it has not replaced previous world views on the nature of illness, disease and individual and societal responses, but rather shifted conceptual space around such understandings (Brown 1995).

I identified symbolic interactionism as being the approach most compatible with the aim of constructing frameworks for chronic illness in general practice. Symbolic interactionism is a dominant school in medical sociology, that has relied heavily upon a tradition of empirical research and accumulation and development of social theory (Turner 1996). Brown (1995), a sociologist, argues the case that such layers of social theory are different variations of constructionism. Constructionism, thus, could be seen as multi-layered and multi-dimensional processes applied in different situations.
This simplified view of social theory is much more amenable to translation into a framework with which to view general practice chronic disease care. Social and psychological measurement approaches to understand chronic illness, disability and quality of life, discussed in the previous section, are limited by the individual’s constructions of illness based upon perceptions that are time and context dependent.

However, within modern medical sociology, and sociology itself, there is an apparent strong divergence of tradition between empirical-based cumulative theory construction in symbolic interactionism and rational choice theory, and radical anthropology and post-modern social theory. In direct contrast to the biomedical classification system (that sees disease as a fact capable of independent existence without a physician even needing to make or construct a diagnosis), radical anthropology and post-modernism view social theory or medical fact as merely a description of actors’ interpretations of their own practice. There is an abandonment of generalisable and universal theorising across cultures and social institutions with an embrace of literary or deconstructive philosophical approaches. Turner (1996) labels this as the ‘weak paradigm of social theory’ in comparison with the traditional empirically-based ‘strong paradigm’ of modern theory construction. Brown (1995) describes those in the weak paradigm as ‘strict or absolute constructivists’, who deny any absolutes or reality outside the actors construction. There are no absolutes. Reality, for example, disease, death, coma, do not exist as absolutes, but are always socially constructed in a particular situation. Kleinman (1981) views the process of medicine variously as ‘labelling’ ‘socially constructing’ or ‘processing the social deviance’ of illness rather than with healing in the context of the social environment (Kleinman and Kleinman 1991). Alternative models of illness management should be endorsed that actively promote ‘healing’.

Healing can be promoted by the production of a coherent self-analysis for their own narrative, thus providing a way to repair the rupture which chronic disease caused in relationship with the world (Kleinman 1988).

‘Contextual constructionists’, on the other hand give credence to the functional existence of biomedical facts or state (for example, diabetes, coma, death). The primary emphasis, of contextual constructivists, however, focuses upon relativities in the how, when, where and why of the existence of a condition or medical classifications rather than accepting them as value-free facts (Brown 1995). Divergences and convergences in the development of social theory that further complicate understanding chronic illness and general practice are discussed in more detail in Chapter 3.
Defining chronic illness for general practice

Without a basic foundational disciplinary base, but dealing with issues crossing many disciplines, general practice needs to further develop its own theories. Issues of definition, finding the 'right' disciplinary perspective and moving between them, makes study of chronic illness and disease complicated. Chronic illness and its care are judged to be important, yet mainstream medicine has not seriously addressed these problems. Considerable inadequacies exist. The clinical approach extols general practitioners to base their clinical management upon scientific evidence. Dealing with psychosocial processes and contextual implementation of biomedical evidence is often labelled the 'art' of medicine and is, by implication, considered peripheral to the central 'scientific' task. While, the clinical literature identifies that biopsychosocial care as essential for better outcomes in childhood chronic illness, frameworks pertinent to clinical care (in adult literature) are fragmented across many domains including disease-based, psychological and sociological studies. The resultant describing and classifying of the personal nature of chronic illness and the psychosocial processes of care in response, as 'non-specific' indicates the lack of coherent frameworks. Such categorisation or framing help to define the responses of the medical profession, society in general, and the self-perception of those afflicted, towards long-term ill-health. Whether disease and medical diagnoses exist as absolute or relative facts, they have a functional reality in society. Illness, being primarily self-defined, is a more diffuse and questionable concept in the medical domain and therefore, it is argued, likely to have variations and inadequate responses to its care.
Chapter 3

Understanding constructions of chronic illness and disease

Medicine is, wrongly, often considered a science usually some art and technology attached. It is rather an undertaking or perhaps an endeavour, which uses science, art and technology to achieve goals of a social nature (Blois 1988)

Abstract

In this chapter, I review the nature of constructivism and the development of social theory in the context of chronic illness and the social responses. Constructivism, in contrast to medical or other empirical approaches that view health and disease as objectively measurable, proposes that the world as a meaningful reality is constructed as human interpretive activity. Health, illness and medical care are social facts.

The ‘lived’ experience of the ill is paramount. An individual’s pathway through their illness is influenced by their trajectories through life (with attendant aspirations, expectations and demands), disease progress and consequent medical treatment. In order to be effective, chronic illness care must respond to the illness in people’s lives.

However, the health care offered to the chronically ill often appears not attuned to the problems they experience. It often seems to be mainly directed to professional interpretations of the problems. Current social constructions of the role of medicine place medical practitioners in an ambiguous position as agents of society to control the social deviance of illness, yet being driven by disease-based models that relegate diagnosis as the most valued skill in medicine. Models of care that incorporate the world view of the ill are currently developmental.

Introduction

The previous chapter provided an overview of the nomenclature and frameworks defining chronic illness and disease. The disease framework predominates in medical care. In addition, it identified a lack of discourse about chronic illness in the mainstream ‘objective’ disciplinary approaches, even those dealing with disability and quality of life. Here, understanding health, illness and quality of life are limited by use of objective measurement paradigms that cannot account for the situation, meaning and process of construction of the individual experience. Constructivist approaches were, thus, identified as having the potential to account for the subjective and contextual nature of illness and to complement other mainstream approaches.
This chapter examines historical ideas, theory and evidence about the construction of chronic illness by those afflicted and the responses of society including the medical profession. Because constructions of chronic illness are themselves socially constructed, it is judged necessary to examine briefly how ideas have been developed and the social context of such developments.

**Understanding social constructivism and social theory**

It is necessary first, to reflect further on divergent approaches, briefly described in Chapter 1 and throughout Chapter 2. For such reflection, I argue that it is necessary to immerse oneself in the paradigms that seek to develop understandings or constructions of chronic illness and disease. The literature, reviewed in previous chapters, represents a ‘polarisation of the two cultures’: those based upon argument and intellectual logic, often referred to as hermeneutic, and those based upon empirical science related to diseases and clinico-pathological aetiology and responses to treatment. However, there is a third culture as well that focusses upon empirically analysing social and psychological phenomena. This intermediary culture appears to be attempting to bridge the gap between medical empirical and hermeneutic approaches to understanding and classifying of chronic disease and illness (Snow 1969). The burgeoning enterprise often appears to be driven by the need for ‘big government or big business’ to control health outputs and have accountability for the health dollar, rather than utilisation or being illness focussed (Quinn-Patton 1986; Duckett 1996). Such approaches aim to standardise or objectify illness and disability, rather than provide understandings that are useful for clinical practice. In the outputs of these different cultures there is as much potential for conflict as for ‘integration’ of theory and evidence to inform action.

All streams of theory and evidence, and clinical practice are fundamentally social constructions. However, apart from the theorists in the hermeneutic stream, most do not recognise that knowledge creation is ultimately a social process. Therefore, I identified the social constructivist paradigm as particularly important. It is not only the discipline that focuses upon understanding illness as fundamental, but is critically reflective on the creation of medical knowledge, the process of disease categorisation and clinical practice.
A social constructivist perspective of chronic illness and disease

Ideas and theories about the nature of illness have a long history of vigorous debate and movement between competing perspectives (Gerhardt 1989). Perspectives that make a major critique of and impact upon modern medicine: functionalism; constructionism and latterly postmodernism, offer a theoretical basis through which to view chronic disease and illness management in general practice. Constructivism emerged as a response to Parsons' (1951) functionalist perspective, which was itself a response to the emergence of biomedicine when disease became located in specific anatomical structures and was reduced to mechanistic processes from the Eighteenth Century, principally by Descartes (Foss and Rothenberg 1987; Turner 1996). For example, Parsons identified the sick role as a social response to the deviance of not being a productive social member due to poor health (Fox 1996). Parsons clearly identified the social role of medicine in processing the deviance of illness. Modern social theory after Parsons owes much of its theoretical framework to diverse schools including symbolic interactionists, the Chicago school, Marxism and more latterly the philosophies of Foucault (Turner 1996).

Berger and Luckman’s (1967) influential text, *The Social Construction of Reality* popularised the major tradition of thought, often referred to as ‘constructivism’. Its theorists proposed that reality is constructed through human action, and the world as meaningful reality is constructed through human interpretive activity. To a constructivist, health, illness and medical care are social facts. The interpretation of a particular behaviour or experience as a sign or symptom of illness depends on cultural values, social norms and culturally shared rules of interpretation. Social constructivism or constructionism has many, often divergent, meanings (Gerhardt 1989; Schwandt 1994). Many authors describe a variety of types of constructivism including one labelled social constructionism. This focuses on ‘the world of intersubjectively shared, social constructions of meaning and knowledge’ in accordance with Berger and Schutz (Schwandt 1994: 127). The term seems have been coined by Gergen (Schwandt 1994:127). Guba and Lincoln use the term ‘constructivist paradigm’ and call their research methodology constructivism (Schwandt 1994:127).
Underlying the many and apparently divergent approaches, social constructionism is a synthesis of symbolic interactionism and structuralist/political/political economic approaches. Depending on the subject matter, one or other of these approaches may predominate (Brown 1995:40).

Symbolic interactionism seeks to uncover the hidden world of everyday interaction and decision making, such as the experiences and meaning of illness to those who are afflicted. Structuralist functionalist approaches focus upon the impact of fundamental structures of power and the organisation of society (Brown 1995). Turner and Samson (1996) argue for the study of illness construction at three levels: the individual (phenomenology), the social (sociology of roles, norms etc.) and societal (political economy of health and illness).

Certain constructions, such as the nature and existence of mental illness as defined by psychiatry, have been particularly challenged by ‘strict constructivists’ for example radical medical anthropologists and the post-modernists. ‘Contextual constructionists’, on the other hand give credence to at least some functional meaning of states classified by biomedicine (eg. diabetes, coma). The primary emphasis, however, focuses upon relativities in the how, when, where, and why of the existence of condition rather than accepting it as an absolute (Brown 1995).

The process of social constructionist logic requires us to ask questions (about health care) such as: Why was action taken or not taken? Who benefits or at least avoids trouble, by identification and action? How do divergent perspectives on the phenomenon merge or clash? How do the experiences of the ill person or the doctors involved affect the course of the disease, as well as the social outcomes of illness? (Brown 1995:38).

Rather than a diagnosis, a given biomedical fact driving management, there is a set of understandings, relationships and actions that are shaped by diverse kinds of knowledge, experience, and power relations. These are constantly in flux.

Part of the constructivist view is that managing illness involves active interpretive work, rather than simple biomedical labelling and its unproblematic consequence. For example, Eisenberg (1986) a constructivist, asserts: patients suffer ‘illnesses’, and
physicians diagnose and treat ‘diseases’. The principal reason for making these
distinctions is that ‘illness’ and ‘disease’ in this school of thought do not stand in a one-
to-one correspondence. They represent the two realms of culturally and medically
defined problems. According to constructionists, the imperative of medical practitioners
is diagnostic classification of deviations from normal patterns of health (Engel 1973).

The experience of illness and quality of life in chronic illness

Chronic illness is a way of being in the world...walking the edge of
tragedy and transformation or rage and grief (Strauss and Corbin 1988)

Literature on the social construction of chronic illness deals mainly with the lay
experience of illness, viewed mostly through a symbolic interactionist approach.
Phenomenological perspectives on personal naturalistic accounts of experiences of
‘lived illness’ provide the basis for such understanding. Interactions between the ill and
others, such as in the doctor-patient relationship, are also fundamental. Glaser and
Strauss (1967) and Glaser (1978) developed the ‘grounded theory’ approach in the
social constructionist tradition. This work produced seminal research into the nature of
the experience of ‘sick people’ with chronic conditions (Strauss and Glaser 1975).

Illness is an ‘internal perception of unpleasant and disruptive bodily sensations’
(Charmaz 1983). Illness is a particular expression of a universal experience of human
existence, namely the threat to personal viability and survival (Gerhardt 1989). This
implies a threat to the individual’s inner and social being by the biological component
of their own body. An individual experiences loss during falling ill. The worst
biographical events are ones that bring about the loss of part of the individual’s
world—with illness this is both in terms of function and survival (Gerhardt 1989). An
additional dimension is that illness is more likely to occur with or is ‘produced’ by
inequalities in society because of social structure and resource distribution (Cartwright

Chronic physical illness, brings disruptive bodily sensations. People with chronic
incurable illness must manage themselves at a private internal level, usually in the
home. This is the major work of chronic illness care (Strauss and Corbin 1988). The
representations of life and meaning of illness that the chronically ill develop
themselves—the private face—form the core of the work of managing illness. The task in chronic illness is to deal with the physical disruption of disease and adjust to the social experience of illness and maintain an acceptable public face (Charmaz 1991; Nijhof 1995). Depending on the severity of the illness, however, this disruption may spill over from the internal into the intimate network and create dependency upon family and friends. Informal family networks provide the majority of unpaid care (Strauss and Glaser 1975). In particular, close female relatives such as mothers or wives, carry the burden (McKeever 1992). More intrusive conditions may create dependency upon formal care, a wide variety of services and inputs from providers from different health and social disciplines. In Australia, such care has been highly fragmented but is currently undergoing reform (COAG 1995).

Stability in the face of chronic ill-health reflects the individual’s ‘sense of coherence’ based upon the comprehensibility, the manageability and meaning of their internal and external environment (Antonovsky 1993). The intrusiveness of chronic physical disease correlates with the degree of stress induced (Rahe 1988; Revicki and Mitchell 1990; Weiland, Pless and Roghmann 1992) and the subsequent development of psychosocial and even explicit psychiatric problems, which in turn worsen physical health. Chronic illness poses major threats to autonomy and control (Agich 1995). People with chronic disease, because of expert knowledge of their own body and their disease, may assume independence maintaining a high degree of autonomy and control (Posner 1988). They may become more ‘expert’ than their general practitioner or even specialist. Those in self-help groups, for example, with access to the latest medical knowledge with the Internet have significant collective expertise (McGuiness 1996).

**Trajectories of illness**

Illness is not static with large fluctuations of pain, distress and suffering related to disease progress and consequent medical treatment. An individual’s pathway through their illness is influenced by the aspirations, expectations and demands of their personal life (Strauss and Corbin 1988). Chronic illness occurs at any stage of the life course and the chronically ill must therefore come to terms with managing a lifelong course of illness.
Medical practitioners and other health professionals almost always treat the acute phase of an illness in an acute care setting. Other phases of illness are primarily managed by the individual, in the home and community with the aid of medical advice and medical regimens. However, the main work is conducted by the chronically ill themselves with the help of their primary network, such as spouses, children, relatives and close friends. Neuling and Winefield (1988) found that the general practitioner was included in this primary network of important support people coping with a serious illness. Such ‘work of ‘managing’ can, and often does, involve the lives and identities of the chronically ill and their families in multiple domains including financial, emotional, sexual, economic, social and vocational. Home is the central site of the work of chronic illness (Corbin and Strauss 1988; Strauss and Corbin 1988).

Social responses to chronic illness - roles and responsibilities

Parsons (1951) pioneered the notion of roles and functions in illness and the idea that medicine is an institution of social control for the deviance of illness, by instituting a ‘sick role’. Parsons’ concept of the ‘sick role’ has been much discussed and is taught widely to medical students, often forming the basis for an understanding of chronic illness and sickness (Armstrong 1989). Therefore it is discussed in some detail. An interesting facet of this work is that it places normative expectations on the medical practitioner and the system, as well as the patient. The patient is expected to relinquish responsibility and to step out of normal roles, but only fleetingly. The patient is not only expected to get better but to want to get better. Chronic disease, however much of an accusation, is viewed by many as fitting uneasily into Parsons’ model. The system that latterly includes advances in technology, demands that the patient, and the disease, respond. In this situation chronic disease, that does not ‘get better’ may be an accusation for the patient, the medical practitioner and the medical system that have failed to produce a cure (Strauss and Glaser 1975). Other ‘deviations’ from this cultural expectation are the hypochondriac patients, who assume the sick role permanently. Some patient’s illnesses become accepted by the family to such an extent that the person’s continued illness becomes one of the pillars of the family’s existence (Doyal 1979). A patient may have a chronic disease, yet assume the ‘sick role’ only intermittently or may have chronic ill health with no diagnosis. Their relationship with the health system is thus rendered more contestable. The medical role, in accordance
with dominant assumptions of the day, was generally a positive social good (Turner and Samson 1996). However, medical students in traditional simplified undergraduate sociological teaching, are not generally exposed to the full range of Parson’s work on the sick role. He also identified a sick role when the goal of complete recovery becomes impractical and the patient must accept regimens of management that will minimise current impairment and future risks (Gerhardt 1989). Parsons also was mindful of the moral and metaphysical questions that surround illness. The exemption from responsibility for having fallen ill conferred upon patients by the sick role and the challenges of coping could accentuate the links of health and illness to the ‘ultimate concerns’ of religion, magic and science (Fox 1996).

Critics of Parsons’ theories come from those who saw the professional construction of illness as problematic rather than as a social good and challenged the social deviance of illness. Those on the political right argued for less social control and greater individual freedom. Those on the political left wanted to change the nature of the power structures that gave medical care into the hands of the powerful ruling elite (Armstrong 1989). The medicalisation of everyday life by the institutionalisation of medicine can at its most extreme reduce individual autonomy, independence and ability to cope. It could represent repressive control by central authorities maintaining what is ‘normal’ (Zola 1972; Illich 1974). Alternatively, medicine can create illness through its processes; iatrogenesis (Illich 1974). The left wing critique principally from a Marxist or neo-Marxist perspective, argues that institutional medicine maintains social inequality between groups. This ensures that the status quo distribution of power is maintained. The predominant ruling class, including the medical profession, exploit the less privileged through the capitalist system of production which in turn shapes the nature of sickness in society (Navarro 1976; Doyal 1979; Waitzkin 1979).

Modern views see the medical practitioner as positioned ambiguously between these two positions. To patients, the medical practitioner can be both a private audience with whom intimate details of illness are shared in order to help them get better, or an audience representing the agents of social control from whom personal details are withheld (Charmaz 1991). The latter may be because of fears of being labelled as complaining; the cultural norms of stoical behaviour especially among men (Waitzkin, Britt and Williams 1994). Disclosure may also threaten an individual’s independence in
areas such as driving, employment, insurance, playing sport, and drinking alcohol etc. (Scrambler 1982). Processes in the medicalisation of chronic illness may be constructive or counterproductive (Woodward, Broom and Legge 1995).

**Constructions of disease**

How do medical practitioners construct disease? The social construction of medical knowledge relates to the medical belief systems and with the process of diagnosis (Armstrong 1989). The traditional model influencing medical practitioners in consultations with patients is the biomedical model. The biomedical model is ‘based upon molecular biology as its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables’ (Engel 1973). Diagnosis is regarded by the leaders of the medical profession as integral to the theory and practice of medicine and is central to the work of all medical professionals (Harrison 1993). Social scientists also view the process of making the diagnosis as central to subsequent constructions of patients’ illness. Diagnosis represents the time and location whereby medical professionals and others determine the existence and legitimacy of the condition (Brown 1995; Turner and Samson 1996). Blaxter (1978) tells us that diagnosis has two meanings: process and category.

Category is the nosological location in medical knowledge where the diagnosis resides. This involves the often reified definitions of disease into which professionals and others fit their observations. Process is the set of interactions which lead to the definition of a category and to its imposition in certain cases.

Differential diagnosis is probably the cognitive skill most rewarded for medical students and practitioners. ‘The role of the doctor is to take undifferentiated or unorganised illness and to arrive at an organised illness’ (Balint 1957).

Most chronic diseases generally have a biomedical definition acceptable to both the lay public and the medical profession. Such diseases include diabetes or asthma, for example. Diagnosis of these ‘mainstream’ chronic diseases is not usually conflictual or controversial. Nonetheless, there may be significant bargaining between medical practitioner and patient about allocating a diagnostic label (Brown 1995). This is particularly the case when such a diagnosis has major life or lifestyle implications.
The biopsychosocial model: a way forward

‘Holistic critiques of allopathic medicine’, sociological critiques of the medical model, and the rise of public health and social medicine, have converged to produce a biopsychosocial model. Such a model attempts to integrate biomedical categories with dimensions including the physical, social and psychological in an individual or in groups (Turner and Samson 1996). For example, living standards and socioeconomic resources are strongly linked to illness and disease causation. The mind-body distinction inherent in the biomedical classification system is breached because it denies the nature of the ‘embodiment’ of the historical, social and cultural context of the person in illness and sickness. Health and illness are seen as aspects of social action, which involves interpretation and choice (Turner and Samson 1996). However, the task of ‘integration’ of theory and evidence to inform action remains challenging.

Recent formulations of the patient role in chronic illness, attempt this integration by emphasising individual autonomy and control. The ‘impaired role’ occurs when the individual has permanent impairment (or illness), but maintains normal responsibilities within the limit of the health condition. The “impaired” accept responsibility for the work of their own health management depending on the implications, personal experience and resources. The major work of managing is predominantly self-care or supportive care by family, friends and peers and takes place mainly at home (Curtin and Lubkin 1986).

The role of medical practitioners is supportive and facilitative except when acute care or diagnostic and clinical skills are required.

Discussion

Contemporary ideas about disease and illness represent an accumulation of historical changes in emphases and understanding in knowledge creation as well as the nature of ill-health. Chronic disease and illness can be seen as medical, societal and personal constructions to manage the irreversible protracted failure of the body.
This chapter reviewed understandings about disease and illness primarily derived from social constructionist approaches and its important precursors and antecedents. Symbolic interactionist approaches, typically micro-level or small scale, focus upon individual understandings. Abstractions of personal accounts from ethnographic or narrative analyses lead to substantive theories about the group and formal theories about society (Charmaz 1990). In contrast, macro-level approaches described as societal and structural, focus upon disease-based clinicopathological categorisation and systems of medical care (Turner 1996). It would seem logical that in order to better understand chronic illness in a clinical or health system setting, several theoretical streams would need linkage and translation. Fielding and Fielding (1986), Quinn-Patton (1986), Rosenfield (1992) and Martin and Peterson (1997) argue that such linkages are appropriate but difficult to achieve in practice, taking account of historical tradition of knowledge construction. Some strict constructionists, including feminist sociologists, (Dubois et al. 1985), anthropologists (Kleinman 1980) and other post-modernists argue that such linkages cannot take place because of a lack of a common knowledge base and assumptions underpinning the creation of knowledge. Reductionist scientists place hermeneutic approaches at the lowest order of ‘evidence’, because they are not (and most often cannot be) subjected to double-blinded randomised control trials (Sackett 1976).

This thesis, takes a different perspective from that of many theorists because it is written by a general practitioner, who needs a pragmatic framework within which to understand chronic illness management in general practice. It seeks to identify practical messages from the various approaches that could be used to inform and improve practice. Social constructionism, despite its complexity and post-modern ‘crisis of representation and the associated instability of meaning’ challenges contemporary professional categorisations of chronic disease and illness and the organisation of medical care (Turner, 1996). Although, there is little agreement about what theory is or what would constitute a theoretical process, the reality of the individual’s illness is constructed through personal actions and those of the medical profession and others related to their illness, disease and treatment. Meaningful reality has been constructed by the interpretive activity of individuals. Interpretations, of the socially constructed medical role (through many years of medical school training), since Parsons, have varied. Medicine has been seen as a positive social force to control the deviance of illness
through cure or the sanctioning a sick role. Subsequently, such social control was considered to maintain powerful elites or curtail individual autonomy. Recently, the role of the medical practitioner has changed and is seen as balancing ambivalently between the positive role of Parsons and the more negative controlling influence. While the process of biomedical diagnosis may serve patients well on many occasions, and is cognitively challenging and rewarding for the medical professions, it must be viewed as a process of social construction or medicalisation that may be helpful or harmful. The goals of general practice are ultimately social although the basic belief system and the tools of medicine are based around the categorisation and classification of disease processes using the scientific method.
Chapter 4

The discipline of general practice and chronic disease and illness

A skilled family doctor... First we must increase our knowledge of the incidence and prevalence of disease, the significance of symptoms etc... Secondly we must learn to analyse, describe and justify the many intuitive judgements we make in the course of a day's work.

(I. R. McWhinney 1972)

The third culture consists of those scientists and other thinkers in the empirical world who, through their work and expository writing, are taking the place of the traditional intellectual in rendering visible the deeper meanings of our lives, rendering who and what we are.

(John Brock 1996)

Abstract

General practice care has several distinct features. It is longitudinal with opportunities for long-term professional and interpersonal relationships between patient, family and medical practitioner. Care can be provided over time and time can be used opportunistically in consultations. Theories of academic general practice articulate generalism as responding to both disease and undifferentiated illness, integrating mind, body and societal perspectives in its care. The generalist or non (biomedical or psychosocial) specialist attempts to provide integrated care despite multiple fragmented specialisms about systems of the body and the mind.

Intellectual traditions in general practice integrate the mind and social context of the body and the disease to construct a psychosocial as well as physical identity for patients. This has been operationalised as the patient-centred model of care that enables the patient to live better with their disease and their illness and optimise their health. However, international literature indicates that, in reality, general practice care is not necessarily attuned to people's needs, particularly in chronic illness.

Biomedical dominance within the health system means that technological and biomedical problems and solutions have primacy, and are supported through economic reward (in Australia, the Medicare schedule), power structures and health service organisation. Generalism may have lower status in specialised medical care and social care hierarchies, unless it continually redefines itself, as specialisms continually expand. The implementation of generalist biopsychosocial care of disease and illness for those with chronic disease appears problematic at theoretical, operational and health-care system levels.

Introduction

In this chapter, I examine particular expectations, contributions and challenges of general practice in relation to chronic disease and illness. Having previously examined the general case of chronic disease and illness and medical care, here I examine the special case of general practice. I will briefly review how general practitioners, both the
academic and clinicians, view the discipline and its roles and responsibilities in relation to current systems of care.

Challenges in disease and illness care in general practice

In Australia, the general practitioner is consulted frequently by the majority of those with chronic disease and illness (ABS 1991). General practice care has several distinct features. It is first 'generalist' dealing with the person as a whole rather than as a series of biomedical parts (McWhinney, 1996; RACGP 1997). It is longitudinal with opportunities for long-term professional and interpersonal relationships between the patient, family and medical practitioner. The doctor-patient relationship has particular relevance because of the long-term nature of care (McWhinney et al. 1997). Care can be provided over time and time can be used opportunistically in consultations with different family members. The key indicator of the value of the work of the general practitioner in the Australian fee-for-service system is time spent in the consultation (Harris et al. 1996).

However, the generalist role of the general practitioner is not well-defined. It has been located as dealing with undifferentiated illness and attempts to integrate mind, body and societal perspectives in its care despite multiple fragmented specialisms about systems of the body and the mind (McWhinney et al. 1997; RACGP 1997). Generalism in primary medical care (general practice) attempts to bridge the broad range of biomedical and psychosocial issues in chronic disease management in the face of the persistent dominance of the clinico-pathological model of care.

A diverse intellectual territory

Several major streams of theory and evidence traverse the terrain of chronic illness and disease and the responses of general practice. Principally, the illness experience literature or 'walking in the shoes' of the afflicted, constructs an understanding of the 'lived experience' and biographical disruption of the afflicted individuals and those involved with their everyday lives. Research is typically based upon an empirical qualitative paradigm. Another major stream is concerned with the health system and social, economic, political and medical reactions to, and organisation of, people’s disease and illness. Theoretical analysis, empirical analysis of material records, and quantitative and qualitative analysis inform this stream. A third stream 'health service evaluation' incorporates both the personal and system approaches to some extent, being concerned with 'health outcomes' and the 'quality of life' of people being treated or cared for by the health or social system at an aggregate micro or macro level. Health service research is highly eclectic depending upon multi-disciplinary inputs and collaboration. Its rules are fluid and at best are 'utilisation' focussed (Quinn-Patton...
1986). A fourth stream that is relevant to the objective of this thesis is the philosophical and intellectual basis for the academic discipline of medicine that translates into theories of clinical action.

General practice, as an intellectual discipline, must develop mechanisms to link historical, philosophical, empirical and clinical traditions. For this to happen, there is a need for integration of different paradigms of thought and methodology. This is in order not only to inform clinicians about best practice but to protect what is essential and best about general practice care.

Indeed, within general practice, there is an emerging tradition of theoretical eclecticism and ‘integration’ articulated by writers including Balint (1957) McWhinney, Howie, Freeling, Douglas, Brodie, Westin (1995) to name a few. The mind and social context of the body has been integrated to construct a psychosocial as well as physical identity for patients. This has been operationalised as the patient-centred model and ‘enablement’ through dealing with co-morbidity physical and psychosocial with adequate consultation time (Stewart, Brown, and Weston 1995; McWhinney, 1996; Howie, 1997). Within this group, Balint (1957) and McWhinney (1996) have been at the philosophical end of the spectrum that has informed clinical practice. Howie (1997) with his Scottish team have operationalised intellectual concepts into empirical research that has influenced health policy about consultation length and patient enablement. Westin (1995) and McWhinney (1996), among others, have argued for a broad spectrum of research, philosophical and disciplinary approaches. Malterud (1995) has adopted traditional sociological approaches as being appropriate for general practice.

Malterud (1995) and Whinney (1996b) have argued for a new epistemology of clinical general practice knowledge because current biomedical paradigms do not adequately inform clinical practice. Malterud (1995) states that theories of knowledge, especially the concept of tacit knowing, seem suitable for description and discussion of clinical knowledge, commonly denoted the ‘art of medicine’.

McWhinney (1996:434) argues that general practice is based upon an organismic rather than a mechanistic metaphor of biology.

A living organism has properties possessed by no machine: growth, regeneration, healing and learning. At its most successful, medicine works in supporting these natural processes. Organismic thinking is multilevel and non-linear. The immanent mind knows the world through bodily feelings. The separation of thinking from feeling, and the regulation of emotion to a limited role—the “body as machine” is replaced by “the embodied mind”.

39
Therefore, general practice is the ‘only major field which transcends the dualistic division between mind and body,’ what has been described as the biopsychosocial model of care (McWhinney, 1996)

**Threats to generalism**

In general practice, while some intellectual theory argues the aspirations and realities of biopsychosocial generalism with continuity in longitudinal medical practice in a primary care setting, the practice is less obviously articulated with the theoretical. For example, in a recent British study, Dowrick and others (1996) found that general practitioners described providing predominantly biomedical, some psychological with very little social care, rather than utilising a biopsychosocial model.

Until recently, general practice has been a cottage industry. Today there is a world-wide trend for the discipline to be ‘captured’ by big government, big business and by the modern trend to ‘quality’ measurement and accountability in an economic rationalist paradigm, with an emphasis on scientific and technological interventions in disease-based care (Westin 1995). There is an urgent imperative to measure what general practice actually does, or else it will be driven by what is measured. Evidence needs to be provided about clinical processes such as chronic illness care that are important but not directly measurable (Martin and Douglas 1993).

**The nature of generalism and chronic illness care**

In this section, I examine key elements of generalism and its relation to chronic disease and illness care. The three elements previously identified are: the doctor-patient relationship, the consultation and its duration and the intellectual and clinical models of care. A fourth element will also be discussed, because it was identified in the focus groups in Chapter 1: the role of the general practitioner in the health-care system and how that shapes generalism.

**The doctor-patient relationship**

McWhinney, in the 1996 William Pickles Lecture, articulates the ‘difference’ between general practice and other medical or non-medical specialities. General practice is the only discipline to define itself in terms of relationships, especially the doctor-patient relationship and to think in terms of individual patients rather than generalised abstractions. Progressive humanistic practice sees part of the activity of medicine as an attempt to understand the meaning of illness for the social actor with negotiation until an acceptable meaning is arrived at for the patient (Straus and Glaser 1975; McWhinney 1996; Turner and Samson 1996). Sociologists such as Parsons (1951) have emphasised the shared understandings between medical practitioner and patient who are seen as acting out roles or socially prescribed patterns of behaviour. Indeed, Tuckett et
al. (1985) notes that Parsons’ theory suggests that patients submit to their medical practitioner and rarely ask for an explanation because of faith in their medical practitioner’s curing capacity, as a representative of the profession. Others, like Friedson (1988) have focussed on the potential conflict in the relationship and the means employed by patients and medical practitioners to achieve their goals. Browne and Freeling (1967) also observed many consultations in terms of the goal-oriented ‘games’ played by each party. Tuckett et al. (1985) found that some patients did not ask questions or explanations of their medical practitioner because they did not feel it was their place and, indeed, that the medical practitioner resented being called to account. In such consultation, tension was noticeable as the medical practitioner and patient were observed ‘to talk at cross-purposes, to change the topic of conversation dramatically and without exploration or acknowledgement, or to spar with each other in a confused and contradictory way’ (Tuckett et al. 1985). In other words, in such relationships, it is the patient’s role to be questioned, and the medical practitioner’s role to be listened to and to instruct.

The results of several studies converge to suggest that serious limitations exist in listening, understanding, and overall effective information exchange in many doctor-patient relationships (Tuckett et al. 1985; Martin and Blass 1989). Tuckett et al. (1985) suggests that there may be distancing mechanisms at work in some situations, as medical practitioners work with misfortune and potential misfortune: illness, disease, pain and even death. Empathising and associating too closely with the patient could be equally painful (in psychological terms) for the medical practitioner. Unfortunately, a great deal of ‘cut and thrust’ occurs in the consulting room with the patient endeavouring to interest the general practitioner in their experience of the illness, and the general practitioner trying equally hard to remain impervious as a means of self-protection. Alternatively, the general practitioner may be attempting to adhere to a biomedical script against the intrusiveness of the personal and the biographical demands within the time constraints of a full waiting room.

In the face of this literature and in response to negative perceptions, Stewart, Brown and Weston (1995) and McWhinney (1996) and others in Canada have spent ten years developing the patient-centred method. The patient-centred method has six components. The patient-centred medical practitioner explores both disease and illness in the consultation, seeking to understand the whole person and finds common ground for negotiation. Patient-centred consultations incorporate prevention and health promotion where appropriate, enhance the doctor-patient relationship, and are realistic in their expectations, aims and outlook.
Studies of outcomes of the doctor-patient relationship in people with chronic illness found that empathy, patient-centredness, patient and medical practitioner expression of negative and positive emotion were positively associated with health outcomes; both subjective-consumer satisfaction and objective hypertension and diabetes control (Stewart 1995). Consultation time of up to 20 minutes was related to ‘enablement’ with more time needed to achieve the same levels of enablement for those with complex chronic conditions (Howie, Heaney and Maxwell 1995). What do these qualities, defined on a cross-sectional basis, become in a long-term relationship? What are the mechanisms for these outcomes? Therapeutic relationships with the development of trust and support in the intense social bonding provides healing (Frank 1961; Bowlby 1973). Balint (1957) with groups of general practitioners qualitatively analysing the management of their own cases came to the conclusion ‘the doctor is the drug’; the most powerful therapeutic intervention was the doctor-patient relationship. Stewart (1995) found that the long-term doctor-patient relationship varied considerably according to need, problem, stage of condition and context. However, she did not specifically study chronic disease encounters.

There is almost no literature on long-term relationships of medical practitioner and patient in chronic disease and illness. The support inherent in such a relationship, that may in some cases be an extremely important relationship has received little attention (Winefield and Katsikitis 1987; Neuling and Winefield 1988).

Consultation duration

The doctor-patient consultation in the surgery occupies most of the time in general practice. Variations in consultation duration represent a sensitivity of general practice to the needs of people with different problems and experiences of distress (Howie et al. 1991). In the United Kingdom, the ratio of long to short consultations provided an indicator of quality of care (Howie et al. 1991; Howie, Heaney and Maxwell 1994). ‘Quality’ of general practice care was linked with greater consultation duration in three major areas: psychosocial care; complex chronic or serious illness care; and health promotion (Wilson et al. 1991). This occurred in both observational and experimental studies. The main consultation outcomes associated with ‘quality’ in longer consultations (generally defined as ten minutes and over) are ‘enablement’, satisfaction and effective resource use (Howie 1991; Wilson et al. 1991). Evidence is strongest for ‘enablement’, which is present if people indicate that they are better able to deal with their health, their illness or their life as a result of the consultation (Howie 1997). In addition, people with chronic and complex problems apparently need more consultation time to achieve similar levels of ‘enablement’ than those with less serious problems (Howie 1997). In Australia, these people (and their general practitioners) have
complained about lack of time in general practitioner consultations, while socially
advantaged families access more preventive care (Weston 1996; Martin 1997).

Patient need for general practitioner care is a complex concept. In the context of
population health, need can be defined in terms of predisposition to worse outcomes
such as premature mortality and excessive morbidity. Need has both health and socio-
demographic components (Feinstein 1993; Machenbach 1994). Health components
include chronic disease, health status and factors leading to worse health such as
smoking. Socio-demographic factors, such as age and social isolation, can predispose to
worse health and greater health-care needs. Other factors, such as education and
occupation, enable better health and uptake of health care (Feinstein 1993; Machenbach
1994). In the United Kingdom, those with the most need for care often have the least
health care utilisation, including general practice: Hart’s Inverse Care Law (Hart 1971;

The intellectual discipline of general practice

International literature on the subject indicates that most of the needs of the chronically
ill are not served by purely disease-based interventions, particularly in the ‘long haul’ of
the chronic phase of illness. The foundation of medical practice, the biomedical model
has been severely challenged. Challenges come from two directions in the main. One
position sees medical practice as a process of social control and ‘out of touch with and
dominating people who are ill’ and rejects to a greater or lesser degree, the medical
model of care. The other position, while critical, sees the problem being a problem of
the foundational scientific basis of medicine. The current scientific paradigm needs to
be transformed to provide integrated biopsychosocial care that is receptive to real-world
complex open systems. The emphasis of this position is on the philosophical and
foundational scientific basis of practice. How to transform the current biomedical
system into an integrated infomedical system which is operational and practical is a
major challenge. As Armstrong (1989) says medicine has instigated a series of new
phenomena and objectives... to deal with the ‘whole person’. However, how
appropriate these interventions and changes of style are, is not clear. Critics see the
intrusion of medicine into the ‘private’ areas of people’s lives as problematic: an
undesirable and pernicious influence and promoting undue control over individuals and
social groups. Others, often within the profession, see the doctor-patient relationship
almost as a panacea for all types of healing. The debates about appropriate social roles
of medical (and other providers) are unresolved in the social constructivist literature
(Armstrong 1989).

The doctor-patient relationship literature highlights the dissonances between the world
views of general practitioners and patients, yet reveals difficulties for general
practitioners at arriving at appropriate 'professional distance' when these dissonances are addressed. Social constructionism and post-modernism, by major focus upon the 'margins' of medical practice: the top specialists in teaching hospitals, those on the extreme of the income generating and technological end, and the uncertain, difficult-to-understand conditions such as chronic fatigue syndrome, RSI etc., ignore the vast bulk of everyday medical practice (Willis 1994). Turner and Samson (1996) acknowledge the difficulty of the general practitioner role in the recently written conclusion to the second edition of Turner's treatise, Medical Knowledge and Social Power (Turner and Samson 1996).

**The general practitioner, social support and chronic care**

Previous sections identified a divergence between theoretical developments in general practice and their application in clinical care (Tuckett et al. 1985; Dowrick et al. 1996). While theoretical frameworks still require further development, it is my contention that the more major problem is a lack of action frameworks for biopsychosocial care akin to clinical algorithms that guide disease management.

McWhinney (1996) and others have delineated the patient-centred method with mechanisms for dealing with the critique of dualism, mechanistic and reductionist approaches to clinical care. However, practising general practitioners and social scientists, alike find difficulties in the operationalisation of the biopsychosocial model. While this may be a cohort effect with newer general practitioners having been taught the biopsychosocial model, Dowrick et al. (1996) found that general practitioners over 35 years of age were in fact more likely to be 'patient-centred'. Why is this the case? What are the problems with operationalising the biopsychosocial model; the key tenet of generalism identified by McWhinney (1996). In chronic disease and illness, generalism or non-dualism is particularly important. However, it becomes clear, that biopsychosocial care is not well operationalised as a form of clinical decision-making. Particularly, social models of health are not well developed. Although social support has been linked to positive health outcomes, and been associated with the doctor-patient relationship, the WONCA Classification Committee (1995) definition of supportive care is something to provide when there is nothing left to offer; hardly a positive model of social care.

I argue that the construct of social support provides a link between theoretical perspectives and general practitioner clinical interventions for both differentiated and undifferentiated illness. These interventions may be actively provided by general practitioners through intervention or referral or result from more naturalistic interactions with their patients over time. However, apart from a few studies in disease-based care, the literature about human interactions and outcomes of general practice care has been
There is considerable potential to integrate many existing general practice studies on non-disease-based clinical actions into a broad conceptual framework, that will allow better theory development and testing. I suggest that social support theory provides such a framework.

The general practitioner’s role is, usually, one of technical competence and concern mainly through supportive care. Supportive care promotes self-management and control in the face of chronicity to minimise physical and psychosocial destabilisation. Support in general practice, as in other situations, can be categorised into functional components, structure and network components and perceived satisfaction with support. Functions include information (providing adequate information and advice), emotional (empathy, caring), appraisal (feedback, reassurance), social (friendship, companionship) and practical dimensions (Thoits, 1995). The long-term doctor-patient relationship with the general practitioner may also contribute to another element of support, the structure of people’s networks (the connection, individuals have to significant others) through availability, familiarity and trust over time (Winefield and Katsikitis 1987). However, the support structure does not necessarily guarantee adequate or appropriate physical or psychosocial support functions in the doctor-patient relationship. Perceptions of support have strong associations with emotional well-being, although they may be governed by limited or unrealistic expectations. The impact of support structure and functional elements on health outcomes in different types of people with chronic illness in Australian general practice is unknown.

**Dilemmas related to the role of the general practitioner in the health-care system**

General practitioners are consulted by people at all stages of chronic illness, being on the interface of the acute or disease-based care in the medical specialties and hospitals, and the chronic or supportive care provided by a wide variety of agencies. However, under existing and new models of ‘managed care’ their task is challenging, dealing with expectations of cure, balancing personal care of an individual with best practice technical guidelines, and increasingly, to ration expensive health services (Schlesinger and Mechanic 1993). The general practitioner, at the bottom of the medical hierarchy, in being asked to be most responsive to ‘client demand’ in a fee-for-service system, and is increasingly asked to conform to ‘evidence’ and protocols still largely dominated by specialist biomedical models. The general practitioner is the object of much of the doctor-patient relationship literature and required to be ‘patient-centred’ and holistic as well as to practise highly interventionist preventive medicine in order to improve ‘outcomes’. Another paradox for general practice is the ‘dominance of caring’ dilemma within health-care professions. Lumby (1996:3) a senior nurse, states
together nurses and doctors offer a gestalt of care which is quite unique. Doctors by necessity, primarily focus upon disease and surgical technique, on diagnosis and prognosis, on treatment and drug regimes. Nurses, in turn, primarily focus on the experience of illness, disability and dying, on education for maintenance and prevention, on adjustment to changed lifestyle and on choices for future health care.

Here we have exemplified the dichotomy of mind and body across professions with nurses staking a claim on the psychosocial ‘caring’. While Lumby (1996) writes from the perspective of the acute hospital paradigm, her view exemplifies the ambiguity about the role of the general practitioner in the community. Particularly as ‘stress’ and lifestyle are seen as the causes of the modern epidemic of chronic illness and disease (Turner and Samson 1996). With the advent of different payment and incentive systems, such as fundholding, mixed systems of remuneration the primary care physician may in fact achieve more power in the system in some areas, but may lose in others. Physicians reported lower perceived levels of autonomy in patient selection and time allocation in the United States of America’s managed care systems, yet also reported higher levels of perceived autonomy in use of hospital care, tests and procedures. However, the use of time and the healing relationship, are key strengths of general practice, and generalists reported less autonomy than specialists in managed care (Baker and Cantor 1993). In the United Kingdom system, despite initial enthusiasm general practitioners expressed increased levels of job stress and dissatisfaction since the introduction of fundholding (Rout and Jaya 1994).

**Discussion**

Chronic physical disease care straddles two major paradigms: the biomedical management of disease, and supporting people in their managing of the physical and psychosocial effects of illness. In practical terms, general practice straddles the acute or disease-based care provided by medical specialties and hospitals and the chronic or supportive care provided by a wide variety of agencies.

Biomedical care is based on ‘objective’ knowledge and constructed external to the general practitioner and the patient around classificatory systems based upon pathophysiological diagnoses. Illness is the unwanted, unpleasant physical and psychosocial experiences of the accompanying disease which is ‘subjective’ and internally constructed by the individual in their unique milieu. Dichotomising of the mind (subjective) and body (objective) is repeatedly argued to be a feature of ‘biomedical dominance’ in the institutionalisation of health care (Willis 1994). Yet, the outcomes in common everyday mainstream chronic physical diseases are determined by
psychosocial processes such as personal and socio-economic resources related to support, stress, and social resources including access to medical care, more than by disease categories such as diabetes (Stein and Jessop 1989; Mathers 1993). However, the key tenet of general practice is generalism: non-dualism, a patient-centred view of medicine and care of illness and disease. However in Chapter 1, evidence from focus groups, and the personal experience of the author, both as a general practitioner and a patient, is that implementing such a model of medical care is problematic. The problems, so far, identified are as follows:

- **Theory and evidence**: rather than a coherent conceptual biopsychosocial framework to inform the ‘action discipline’ of general practice, there are fragmented and competing paradigms and disciplines within those paradigms providing incomplete fragmented evidence without links between objective and subjective elements of chronic disease and illness.

- **Categorisation**: nomenclature is dominated by disease-based ‘objective’ categories, although multiple non-disease-based ‘objective’ categorisations of ‘subjective’ experiences exist they are often atheoretical, unlinked to the ‘subjective’ meanings people place on their illness.

- **Lack of operational frameworks**: because of lack of coherent theory and models in academia and health services, and current categorisations of interventions; operational frameworks for clinical action of objective, subjective and inter-subjective dimensions of chronic illness and disease are absent.

- **The construction of the system of health care**: because of the lack of operational categorisations of clinical actions of chronic illness care and the functions of generalism, much of the role of the general practitioner appears unrecognised, unrewarded and unsupported.

In the next two sections I will, therefore, examine how general practice biopsychosocial care, operationalised as supportive processes, is constructed for people with chronic illness in Australia. I will conduct macro-level system studies and micro-level phenomenological studies with both quantitative and qualitative elements. I examine the consultation, its processes and duration, the doctor-patient relationship and how clinical and social support needs and wants are constructed by general practitioners and patients alike, in reference to a constructivist theoretical framework incorporating contemporary general practice intellectual theory.
Part 2

What happens in practice

The Macrolevel:

the general practice system
Chapter 5

Chronic disease in childhood, adulthood and old age:


Abstract

This chapter provides a broad overview of contemporary general practice management of chronic disease: physical, psychological or both together. It asks the question: Are chronic physical conditions managed mainly as physical diseases or as bimodal entities combining disease-based care with physical and psychosocial support components?

A secondary analysis of the Australian Morbidity and Treatment Survey (a national survey of general practitioners documenting their consultations over two weeks) was conducted. A 'chronic condition list' identified encounters at which chronic diseases were managed. Adult and childhood encounters were analysed separately, and patterns of care were explored using statistical techniques including logistic regression.

Children: Almost 16 per cent of childhood encounters included a chronic disease diagnosis. Asthma accounted for half of the diagnoses recorded, and ten diseases accounted for 88 per cent. The main reasons for encounter were: management of acute respiratory infections (ARI), other acute common childhood problems, prescriptions and immunisation. Referrals when they occurred were to medical specialists but not to other agencies. Multiple diagnoses, a psychological diagnosis and less continuity, but not chronic disease diagnoses, independently predicted the documentation of psychosocial care in encounters.

Adults and older people: General practitioners described chronic physical conditions in 42 per cent of all male and 39 per cent of all female adult encounters. Percentages increased with age, with over 60 per cent of encounters in the 65 plus age group including a chronic physical condition. Encounters with a psychological diagnosis accounted for 7.2 per cent of all adult encounters. Sixty-seven per cent of these encounters were with women. Chronic physical condition encounters were associated with few psychosocial or physical support interventions including referrals. This pattern persisted whether or not psychological conditions were also diagnosed in the same encounter. In contrast, psychological encounters without a chronic physical diagnosis had high levels of psychosocial support interventions, but less practice continuity, fewer problems, longer consultations and were with a younger age group.

Mid-career male GPs without postgraduate qualifications are more likely to treat chronic disease patients with or without a psychosocial diagnosis, while females with qualifications are more likely to provide psychosocial counselling and support.

General practitioners provided a broad range of 'non-categorical' or non-disease-based care required for children and adults with chronic conditions. However, levels of documentation of 'non-categorical' care: advice, health promotion, psychosocial care, and referral to agencies other than specialists, are low in this cross-sectional sample. Multiple diagnoses or a psychological diagnosis, appear to indicate an intensity of need for 'non-categorical care' independent of continuity status. It is argued that both of these analyses of large representative samples support a mind-body dichotomy in general practice chronic disease care.
Introduction

This chapter provides a broad overview of contemporary general practice management of chronic physical conditions, with psychological conditions of probable, but indeterminate chronicity as a contrast. It aims to address two questions: ‘What are the patterns of chronic disease in Australian general practice consultations?’ and ‘Are chronic physical conditions managed mainly as physical diseases (the acute care paradigm) or as bimodal entities combining disease-based care with physical and psychosocial support components (the chronic care paradigm)?’ Non-categorical or non-disease-centred chronic care addresses biopsychosocial needs of the child and its family (Perrin et al. 1993). These biopsychosocial factors have a major impact upon outcomes and costs of care irrespective of diagnostic classification (Stein and Jessop 1989; Arpin et al. 1990). In several studies of adults and children with chronic illness, psychosocial adjustment and family functioning had much stronger associations with service utilisation, including hospitalisation, than disease severity or prognosis (Stein and Jessop 1989; Arpin et al. 1990; Browne et al. 1990; Jessop and Stein 1991; Stein and Jessop 1991). One study found a statistically significant and economically important linear gradient in treatment costs with better psychosocial adjustment (Browne et al. 1990). Supportive care processes in primary care medicine that are well co-ordinated can ameliorate psychosocial factors synergistically compounding the burden of chronic disease impact. A randomised control trial has shown that these improvements persist and amplify over five years (Stein and Jessop 1991).

The Australian Morbidity and Treatment Survey (AMTS) 1991-92 provides the only national data on general practitioner clinical management practices (Bridges-Webb et al. 1992). The survey describes: (1) the range of chronic conditions treated in general practice consultations; (2) the reasons for encounter in those consultations; and (3) general practitioner management with an emphasis on general and supportive as well as disease-based interventions. Characteristics of encounters with chronic physical, psychological conditions, or both, are compared in an effort to understand how Australian general practitioners are labelling and managing chronic disease.

Methods

The AMTS described 98,769 patient encounters provided by a random sample of Australian general practitioners during 1990-1991 (Bridges-Webb et al. 1992). (See Appendix 1 for the Doctor Encounter Recording Instrument and Doctor Questionnaire) A stratified national sample of 3.5 per cent of active general practitioners were recruited with the less populated State and Territories, namely the Australian Capital Territory, the Northern Territory, and Tasmania being oversampled to provide sufficient encounters for analysis. Two versions of the AMTS dataset were used in this analysis.
Descriptive statistics on the complete dataset, weighted to compensate for oversampling, were provided by the Family Medicine Research Unit. Comparative analysis within the dataset was also performed using the unweighted dataset made available through the National Social Science Data Archives.

Chronic physical condition encounters were defined as encounters at which at least one chronic physical disease, condition or syndrome was recorded as a problem. Chronicity was defined by the lack of ‘curability’ and expected long duration of the conditions (Perrin et al. 1993). The Dutch International Classification of Primary Care (ICPC) chronic ‘condition list’ was used to determine which diagnoses represented chronic physical conditions (Lamberts and Woods 1987; Knottnerus, Metsemakers and Limonard 1992). Hypertension was included as a chronic condition, because although it initially represents the latent phase of vascular disease, it becomes long-term and incurable requiring medication and involving the experience of illness. Psychological encounters of probable, but ultimately indeterminate chronicity, were selected using the Dutch ICPC (Knottnerus, Metsemakers and Limonard 1992).

In the childhood encounters, I used Weiland, Pless and Roghmann’s (1992) classification to categorise chronic diseases (already classed into ICPC code groups by the Family Medicine Research Unit) into ‘serious’, ‘minor’, ‘psychological’ and ‘communication’ disorders. ‘Serious chronic’ disease involved all bodily parts other than the skin and external mucous membranes that were labelled ‘minor’. ‘Minor’ chronic disease thus included conditions such as atopic dermatitis, nappy rash and hayfever. A preliminary analysis demonstrated that the profiles of consultations at which ‘minor’ conditions were managed were almost identical with non-chronic disease encounters. Subsequently, ‘minor’ was regrouped with the non-chronic disease group because of this similarity, although some cases of skin and mucous membrane chronic disorders can be problematic over long periods of time. ‘Communication’ that is speech, hearing, autism, dyslexia etc. were diagnosed in very small numbers and were categorised with ‘serious’ because of the similarity of profiles.

Supportive care was defined as either psychosocial or physical. In the absence of predetermined scales of psychosocial support, I designated as psychosocially supportive, any consultations in which psychosocial counselling, emotional support interventions in the consultation or referral were documented. The prescription of psychotrophic drugs was both considered separately and in combination with psychosocial care. Physical support included all variables describing advice and counselling about drugs, treatment and life-style, and health promotion.
The following variables from the AMTS were included in the analyses: patient descriptors: age, sex; practice continuity; diagnostic groupings: reasons for encounter, problems and their management: diagnoses, new or old problem; encounter or process descriptors: treatment or scripts given, and new referrals, tests, investigations ordered/undertaken, procedures and processes, and whether the general practitioner advised a follow-up visit within the next three months, and general practitioner and general practice characteristics: gender, age, vocational registration, place of graduation; practice size, and whether country or metropolitan.

General practice attenders were grouped according to stages in the lifecycle. Children were grouped into ages using the convention of the majority of chronic illness studies, namely pre-school (under five years) and school age (five to 14 years). Fifteen to 50 year olds were grouped to represent those in the adult reproductive and child rearing ages (5,477 encounters). Fifty-one to 64 year olds represented those who were in late adulthood pre-retirement (4,786 encounters). The over 65 year olds represented the retired and older aged group (9,455 encounters).

Descriptive, bivariate and multivariate statistical techniques were used in the analysis. Outcome variables used in the study were the various characteristics of three types of chronic disease encounters, as documented by general practitioners. I categorised these consultations post hoc as those managing chronic physical conditions, psychological conditions and both chronic physical and psychological conditions and other consultations. The outcome variables are dichotomous, therefore logistic regression is an appropriate method to use to identify explanatory variables. Because types of encounter and supportive management are likely to cluster around particular general practitioners, the Generalised Estimating Equation (GEE) approach of Liang and Zeeger (1986) as implemented in SAS (SAS-Institute 1985) was used in every model. This was to provide appropriate estimates of the standard errors of the beta coefficients of the logistic regression models taking into account correlations between patients of the same general practitioner. All independent variables were either dichotomous or treated as an ordered scale. The most parsimonious model was chosen using step-wise model selection procedures. To assess the robustness of the final model, it was chosen using both forward and backward selection and the resulting models compared. The final approaches from these models were, however, always identical.

The limitations of the AMTS for this analysis, are that it is cross-sectional without historical information. Diagnosis was coded post hoc by research assistants using the ICPC classification system. In addition, it is encounter rather than patient-based containing no indicator of condition duration, prognosis, patient (or general practitioner) perceptions of the degree of illness or social circumstances. Its strength is that it is the
only national survey of general practitioners describing their broad processes of care. The degree of under-recording of processes, such as supportive care, is not known.

Results: Children

Profiles of chronic physical and psychological conditions in general practice encounters

Greater percentages of chronic disease were recorded in encounters with males and older children (see Figure 5.1). This almost reached 20 per cent in male encounters in the five to 14 year age group, while the overall percentage was 15.7 per cent. Ninety-six per cent of chronic disease encounters had only one chronic diagnosis, while 55 per cent had one diagnosis and 39 per cent had two diagnoses. Asthma, accounting for half of chronic disease encounters recorded, was present in nine per cent of all childhood encounters (see Table 5.1). Fifty-nine chronic diagnoses were identified in total. Eighty-eight per cent of chronic disease encounters were identified by the ten most common diagnoses. At the other end of the spectrum, forty-nine of the diagnoses identified fewer than one per cent of encounters. Chronic disease encounters were divided into two groups: 'serious' and psychological, using Weiland, Pless and Roghmann's (1992) definitions. Thirteen and a half per cent of the Australian sample had a 'serious' diagnosis of which 78 per cent was asthma and 5.6 per cent involved the central nervous system. Psychological diagnoses accounted for 1.3 per cent of chronic diagnoses.

Figure 5.1: Age-sex distribution encounters with at least one chronic disease recorded as a percentage of all encounters in children under 15 years (weighted data) (chronic disease encounters = 2,464; total encounters = 15,654).

Diagnoses (ICPC codes)

<table>
<thead>
<tr>
<th>Diagnoses (ICPC codes)</th>
<th>Frequency</th>
<th>Percentage of childhood chronic disease encounters</th>
<th>Percentage of all childhood encounters**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>1373</td>
<td>53.5</td>
<td>9</td>
</tr>
<tr>
<td>Contact dermatitis</td>
<td>386</td>
<td>15</td>
<td>2.5</td>
</tr>
<tr>
<td>Hayfever</td>
<td>225</td>
<td>8.8</td>
<td>1.4</td>
</tr>
<tr>
<td>Atopic eczema</td>
<td>72</td>
<td>2.8</td>
<td>0.7</td>
</tr>
<tr>
<td>Migraine</td>
<td>45</td>
<td>1.7</td>
<td>0.3</td>
</tr>
<tr>
<td>Chr tonsillar enlargem</td>
<td>40</td>
<td>1.6</td>
<td>0.3</td>
</tr>
<tr>
<td>Chr lymphadenitis</td>
<td>34</td>
<td>1.3</td>
<td>0.2</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>29</td>
<td>1.3</td>
<td>0.2</td>
</tr>
<tr>
<td>Obesity</td>
<td>28</td>
<td>1.1</td>
<td>0.2</td>
</tr>
<tr>
<td>Congen m/skel anomalies</td>
<td>26</td>
<td>1.0</td>
<td>0.17</td>
</tr>
</tbody>
</table>

*Chronic disease was defined according to the Dutch ICPC list and includes ‘serious’, minor, speech and psychological or mental health.

| Table 5.1: The most common chronic diseases* diagnosed in encounters of children under 15 years at which one chronic disease had been recorded (weighted data). (Total number of diagnoses = 59; chronic disease encounters = 2,567; total encounters = 15,654).


| Table 5.2: The most common reasons for encounter recorded by general practitioners in encounters at which a chronic disease* had been diagnosed in children under 15 years (weighted data). (Chronic disease encounters = 2,567).

**Perceived needs and processes in chronic disease encounters**

Why do children with chronic disease go to see a general practitioner? An analysis of general practice-recorded reasons for encounter was conducted (see Table 5.2). This showed upper respiratory tract infection/symptoms (cough, sneezing) recorded in around one-third of consultations; asthma and wheeze in 12 per cent, other respiratory problems in three per cent, and prescriptions and immunisations in about two per cent. All mental health or psychosocial reasons for encounter combined were recorded in two per cent of chronic disease encounters. Similar patterns emerged in the other problems managed in chronic disease encounters. Acute respiratory and common conditions, and immunisations were the majority.

**Encounter patterns**

What are the patterns of referral in chronic encounters? Eighty-five per cent of referrals in all childhood encounters occurred in chronic disease encounters. Referrals to specialists, mainly paediatricians (excluding psychiatrists) occurred in seven per cent of all chronic encounters (see Table 5.3). Referrals to allied health professionals, (excluding psychosocial referrals) were described in less than one per cent of chronic encounters. Psychosocial referral identified a referral to psychiatrists, counsellors, occupational therapists, psychologists; referral for relaxation or hypnotherapy; drug and alcohol problem treatment; and referrals for social support services, including self-help groups, and community services. Psychosocial referrals were recorded in less than one per cent of chronic disease encounters.

<table>
<thead>
<tr>
<th>Diagnosis (ICPC)</th>
<th>Frequency and percentage of chronic physical disease encounters with psychosocial intervention*recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>12 (9.9%)</td>
</tr>
<tr>
<td>Abdominal hernia</td>
<td>5 (35%)</td>
</tr>
<tr>
<td>Congenital anomaly musculo-skeletal</td>
<td>4 (0.3%)</td>
</tr>
<tr>
<td>Acquired Deformity of limbs</td>
<td>4 (25%)</td>
</tr>
<tr>
<td>Hayfever</td>
<td>3 (1.3%)</td>
</tr>
<tr>
<td>Chronic Tonsillar enlargement</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Migraine</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Adolescent behaviour problem</td>
<td>2 (66%)</td>
</tr>
<tr>
<td>Psychosis</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Obesity</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1 (9%)</td>
</tr>
</tbody>
</table>

*(psychosocial counselling, reassurance or support in the consultation)

Table 5.3: Encounters for children under 15 years, at which a chronic disease and psychosocial intervention were recorded (weighted data) (N=44)

Source: Bridges-Webb et al. (1992) Australian Morbidity and Treatment Survey

How have general practitioners recorded their psychosocial management of chronic disease? General practitioners recorded 'psychosocial counselling, or reassurance and
support’ interventions in 44 (1.7%) of chronic disease encounters (see Table 5.3). Less than one per cent of asthma encounters were recorded as having a psychosocial intervention, while other systemic diseases such as diabetes, migraine and epilepsy encounters had frequencies of five to eight per cent. Interventions were recorded at much higher rates when mental or psychosocial diagnoses were made (in 66 to 100 per cent of cases).

Abdominal hernia consultations had interventions in a third of cases and acquired deformities of the limbs in a quarter of cases. Psychosocial care, combining psychosocial intervention in the consultation ‘counselling, emotional reassurance support’, and referral were recorded in under two per cent of encounters similar to percentages of psychological diagnoses and reasons for encounter.

How do chronic disease encounters differ from other encounters?

In order to examine the most important characteristics of ‘serious’ chronic disease, a logistic regression analysis was performed. ‘Serious’ chronic disease encounters compared to other encounters were entered as the outcome or dependent variable for the logistic regression analysis. All patient, diagnostic and encounter variables were entered as explanatory or independent variables.

<table>
<thead>
<tr>
<th>Characteristics of GP consultations at which ‘serious’ chronic physical disease was managed compared with other consultations</th>
<th>Adjusted odds ratio and 95% confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of diagnoses in encounter 2 vs 1</td>
<td>4.69 (4.08-5.4)</td>
</tr>
<tr>
<td>3 vs 1</td>
<td>8.91 (6.67-11.91)</td>
</tr>
<tr>
<td>4 vs 1</td>
<td>24.56 (9.79-61.62)</td>
</tr>
<tr>
<td>Advice about lifestyle, drugs treatment and health promotion (Yes vs no)</td>
<td>0.64 (0.56-0.74)</td>
</tr>
<tr>
<td>Psychosocial care** in consultation or by referral (Yes vs no)</td>
<td>0.59 (0.44-0.79)</td>
</tr>
<tr>
<td>Specialist referral (Yes vs no)</td>
<td>1.58 (1.28-1.94)</td>
</tr>
<tr>
<td>Continuity - doctor-initiated 3 month follow-up post encounter (Yes vs no)</td>
<td>2.85 (0.98-8.28)</td>
</tr>
<tr>
<td>Sex (Female vs male)</td>
<td>0.77 (0.69-0.86)</td>
</tr>
<tr>
<td>Age group (1-4 vs &lt;1 yrs)</td>
<td>2.93 (2.33-3.70)</td>
</tr>
<tr>
<td>(5-14 vs &lt;1 yrs)</td>
<td>3.51 (2.80-4.39)</td>
</tr>
<tr>
<td>Practice continuity (Seen previously in practice vs new to the practice)</td>
<td>1.25 (1.04-1.92)</td>
</tr>
</tbody>
</table>

All variables entered as factored variables. GP entered as a random effect.

*Psychosocial care refers to psychosocial intervention (counselling support reassurance etc in encounter) and/or referral to psychological, social, rehabilitative, social welfare, self-help agencies.

“Serious” refers to all chronic diseases or conditions other than those labelled as minor or psychological under Weiland, Pless and Rojhman’s classification.

Table 5.4: Logistic regression with a random effects model of factors best explaining the differences between ‘serious’ chronic disease encounters and all other encounters (unweighted AMTS data).

Source: Australian Morbidity and Treatment Survey Data from National Social Science Data Archives
Table 5.4 reports the significant distinguishing characteristics of a ‘serious’ chronic disease encounter. These were greater numbers of diagnoses per encounter, greater practice continuity with more specialist referrals. Males and older children were more likely to have a serious consultation. Both psychosocial care in the consultation or by referral and advice about lifestyle drugs and health promotion were less likely in a ‘serious’ consultation. General practitioner request for follow-up in the next three months almost reached significance.

**What factors predict psychosocial care**

The low level of psychosocial care recording was explored further. Possible explanatory factors (describing patient and encounter characteristics) were entered into logistic regression analysis to predict the outcome of having psychosocial care recorded. Psychosocial diagnosis, and multiple diagnoses, especially more than four in an encounter, were highly significant positive predictors of psychosocial care (see Table 5.5). Being younger or a new patient, with less problem continuity, also predicted psychosocial intervention. Having a ‘serious’ chronic physical disease, with or without a psychological diagnosis in the encounter, were not significant predictors. Advice and health promotion, specialist referrals, and the number of reasons for encounter were not significant predictors.

<table>
<thead>
<tr>
<th>Characteristics of childhood consultations at which a psychosocial intervention was reported</th>
<th>Adjusted odds ratios and 95% confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological diagnosis without <strong>‘serious’ diagnoses in encounter (Yes vs no)</strong></td>
<td>9.58 (5.83-15.76)</td>
</tr>
<tr>
<td>Number of diagnoses in encounter</td>
<td></td>
</tr>
<tr>
<td>2 vs 1</td>
<td>2.08 (1.68-2.58)</td>
</tr>
<tr>
<td>3 vs 1</td>
<td>4.60 (3.05-6.94)</td>
</tr>
<tr>
<td>4 vs 1</td>
<td>14.53 (5.43-38.85)</td>
</tr>
<tr>
<td>Continuity - doctor-initiated 3 month follow-up post encounter (Yes vs no)</td>
<td>0.66 (0.55-0.79)</td>
</tr>
<tr>
<td>Sex (Female vs male)</td>
<td>0.76 (0.65-0.88)</td>
</tr>
<tr>
<td>Age group (1-4 vs &lt;1 yrs)</td>
<td>0.57 (0.46-0.71)</td>
</tr>
<tr>
<td>(5-14 vs &lt;1 yrs)</td>
<td>0.57 (0.46-0.70)</td>
</tr>
<tr>
<td>Practice continuity (Seen previously in practice vs new)</td>
<td>0.76 (0.61-0.96)</td>
</tr>
</tbody>
</table>

*Psychosocial care refers to psychosocial intervention (counselling support reassurance etc in encounter) and/or referral to psychological, social, rehabilitative, social welfare, self-help agencies

**‘Serious’ refers to all chronic diseases or conditions other than those classed minor such as hayfever or dermatitis or psychological.

All variables entered as factored variables. GP entered as a random effect.

Table 5.5: Logistic regression model with random effects of factors best predicting the reporting of psychosocial care* in all childhood encounters (unweighted AMTS data).

*Source: Australian Morbidity and Treatment Survey Data from National Social Science Data Archives*
Results: Adults and the elderly

Profiles of chronic physical and psychological conditions in encounters

General practitioners described chronic physical conditions in 42 per cent of male and 39 per cent of female adult encounters. Percentages increased with age, with over 60 per cent of encounters in the 65 plus age group including a chronic physical condition (see Table 5.6). Encounters with a psychological diagnosis accounted for 7.2 per cent of all adult encounters. Sixty-seven per cent of these encounters were with women, 32 per cent were with men.

Table 5.7 describes the most common diagnoses selected to represent chronic physical and psychological conditions. Hypertension was the most common chronic condition recorded in all age groups. Asthma was the second most common in the 18 to 50 years moving to lower percentages in the older age groups. Lipid disorders were second and diabetes third in the 51 to 64 years; replaced by heart failure in second place and ischaemic heart disease (if related diagnoses are combined) in the 65 plus age group.

The top ten conditions identified 60 per cent of chronic physical encounters. The remaining 40 per cent of encounters covered a wide range of less common conditions (over 100).

Minor chronic physical conditions such as hay-fever and dermatitis accounted for less than ten per cent of chronic conditions diagnosed. They were not included in the chronic disease group in subsequent analyses because they resembled non-chronic conditions in encounters (in terms of continuity, number of diagnoses etc.).

The commonest diagnoses in the psychological encounters were in descending order: anxiety disorder, depression, schizophrenia, dementia, affective-psychosis, and other neurosis. These accounted for 96 per cent of all psychiatric diagnoses. Dementia was the third most common in the 65 plus age group, while anxiety followed by depression were the commonest diagnoses in all groups.

Psychological conditions were recorded in 8.7 per cent of chronic physical encounters, compared with 6.1 per cent in encounters without chronic physical diagnoses. The top five co-morbidities managed in chronic physical encounters were: insomnia, anxiety disorder, URTI/head cold, depression and acute bronchitis.
<table>
<thead>
<tr>
<th>Age group</th>
<th>Chronic Physical condition encounters</th>
<th>Psychological encounters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>18-50</td>
<td>3826</td>
<td>5311</td>
</tr>
<tr>
<td>51-64</td>
<td>3445</td>
<td>4178</td>
</tr>
<tr>
<td>65+</td>
<td>6007</td>
<td>8808</td>
</tr>
</tbody>
</table>

Table 5.6: Age-sex distribution of chronic physical condition and psychological diagnosis in adults 18 years and older (Total adult encounters = 93,612)

Source: Bridges-Webb et al. (1992) Australian Morbidity and Treatment Survey
<table>
<thead>
<tr>
<th>Chronic Physical Conditions (ICPC)</th>
<th>Percentages (Ranking)</th>
<th>Psychological condition (ICPC)</th>
<th>Percentages (Ranking)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18-50yrs</td>
<td>51-64yrs</td>
<td>65+yrs</td>
</tr>
<tr>
<td>Hypertension</td>
<td>14.37 (1)</td>
<td>27.63 (1)</td>
<td>24.43 (1)</td>
</tr>
<tr>
<td>Asthma</td>
<td>10.21 (2)</td>
<td>4.45 (5)</td>
<td>3.20</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.71</td>
<td>5.29 (3)</td>
<td>5.22 (4)</td>
</tr>
<tr>
<td>Osteoarthritis general</td>
<td>2.08</td>
<td>4.56 (4)</td>
<td>5.44 (3)</td>
</tr>
<tr>
<td>Lipid disorder</td>
<td>4.49</td>
<td>7.31 (2)</td>
<td>2.65</td>
</tr>
<tr>
<td>Heart failure</td>
<td>0.21</td>
<td>1.31</td>
<td>7.09 (2)</td>
</tr>
<tr>
<td>Contact dermatitis</td>
<td>7.53 (3)</td>
<td>3.07</td>
<td>2.41</td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>0.73</td>
<td>2.97</td>
<td>4.68 (5)</td>
</tr>
<tr>
<td>Emphysema/copd</td>
<td>0.50</td>
<td>2.18</td>
<td>4.26</td>
</tr>
<tr>
<td>Osteoarthritis spine</td>
<td>2.47</td>
<td>2.84</td>
<td>2.27</td>
</tr>
<tr>
<td>Skin malignant neoplasm</td>
<td>1.83</td>
<td>2.56</td>
<td>2.63</td>
</tr>
<tr>
<td>Hay fever</td>
<td>5.81 (4)</td>
<td>1.47</td>
<td>0.80</td>
</tr>
<tr>
<td>Multiple joint symptoms</td>
<td>2.50</td>
<td>2.03</td>
<td>1.85</td>
</tr>
<tr>
<td>Obesity</td>
<td>4.8 (5)</td>
<td>2.03</td>
<td>0.50</td>
</tr>
</tbody>
</table>

Table 5.7: Most common chronic physical and psychological diagnoses in chronic physical condition (n=32,009) and encounters with a psychological diagnosis (n=5,298) respectively, described by percentages and descending rank order. (Total adult encounters = 93612)

Source: Bridges-Webb et al. (1992) Australian Morbidity and Treatment Survey
<table>
<thead>
<tr>
<th>Reasons for encounter in chronic physical condition consults</th>
<th>Per cent of chronic consults 18-50 years n=15142</th>
<th>Per cent of chronic consults 51-64 years n=13234</th>
<th>Per cent of chronic consults 65+ years n=25733</th>
<th>Reasons for encounter in consults with psychological diagnoses</th>
<th>Per cent of psych consuls 18-50 years n=3814</th>
<th>Per cent of psych consuls 51-64 years n=2083</th>
<th>Per cent of psych consuls 65+ years n=3438</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac check-up</td>
<td>5.52</td>
<td>12.36</td>
<td>12.66</td>
<td>Prescriptions</td>
<td>10.19</td>
<td>15.35</td>
<td>14.48</td>
</tr>
<tr>
<td>Prescription</td>
<td>6.95</td>
<td>10.72</td>
<td>12.06</td>
<td>Anxiety</td>
<td>10.65</td>
<td>9.25</td>
<td>7.83</td>
</tr>
<tr>
<td>General check-up</td>
<td>1.63</td>
<td>2.03</td>
<td>3.47</td>
<td>Depression</td>
<td>10.84</td>
<td>8.23</td>
<td>6.59</td>
</tr>
<tr>
<td>Cough</td>
<td>2.95</td>
<td>2.37</td>
<td>2.12</td>
<td>Cardio check-up</td>
<td>1.28</td>
<td>5.81</td>
<td>6.79</td>
</tr>
<tr>
<td>Back complaint</td>
<td>2.25</td>
<td>2.60</td>
<td>2.31</td>
<td>Insomnia</td>
<td>4.29</td>
<td>3.74</td>
<td>4.86</td>
</tr>
<tr>
<td>Rash</td>
<td>3.75</td>
<td>2.15</td>
<td>1.58</td>
<td>General weakness</td>
<td>3.88</td>
<td>2.76</td>
<td>3.20</td>
</tr>
<tr>
<td>Hypertension</td>
<td>1.46</td>
<td>2.57</td>
<td>2.58</td>
<td>Genl check-up</td>
<td>1.27</td>
<td>2.08</td>
<td>2.66</td>
</tr>
<tr>
<td>Test results</td>
<td>2.26</td>
<td>2.75</td>
<td>1.77</td>
<td>Back complaint</td>
<td>1.72</td>
<td>1.86</td>
<td>1.76</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>2.96</td>
<td>1.80</td>
<td>1.41</td>
<td>Acute stress</td>
<td>2.68</td>
<td>1.43</td>
<td>0.95</td>
</tr>
<tr>
<td>Headache</td>
<td>3.31</td>
<td>1.76</td>
<td>0.75</td>
<td>Headache</td>
<td>1.99</td>
<td>2.48</td>
<td>0.96</td>
</tr>
<tr>
<td>Dyspnoea/sob</td>
<td>0.94</td>
<td>0.99</td>
<td>2.48</td>
<td>Abdominal pain</td>
<td>1.41</td>
<td>1.60</td>
<td>1.14</td>
</tr>
</tbody>
</table>

Table 5.8: Most common reasons for encounter in chronic physical condition encounters(n=32,009) and encounters with a psychological diagnosis(n=5,298) in adults.

Source: Bridges-Webb et al. (1992) Australian Morbidity and Treatment Survey
In psychological encounters the top five ‘other problems’ managed were: hypertension, oesteoarthritis, diabetes, symptoms of the menopause, heart failure and URTI/head cold.

**Why do people with chronic problems go to see a general practitioner? Reasons for encounter**

The top ten reasons for encounter in the chronic physical condition consultations, as coded by general practitioners were, in descending order: cardiac check-up, prescription, general check-up, cough, back complaint, rash, hypertension, test results, abdominal pain, and headache. These presented in 40 per cent of chronic condition encounters. In the psychiatric group, the top ten reasons occurred in 48 per cent of encounters. In descending order, these were: prescription, anxiety, depression, cardiac check-up, insomnia, general weakness, general check-up, back complaint, acute stress, and headache (see Table 5.8).

**Interventions**

‘Psychosocial counselling, or reassurance and support’ was recorded in 0.9 per cent of chronic physical condition encounters compared to 28 per cent of encounters of those with a psychiatric diagnoses (see Table 5.9). In encounters without physical or psychiatric diagnoses psychosocial interventions were not reported.

Eighty-five per cent of referrals in all adult encounters occurred in chronic encounters. Referrals to specialists (excluding psychiatrists) occurred in seven per cent of all chronic encounters; while referrals to allied health professionals (excluding psychosocial referrals) occurred in 0.09 per cent of encounters. Psychosocial referrals were recorded in 0.02 per cent of chronic illness encounters. A psychosocial referral was defined as a referral to psychiatrists, counsellors, occupational therapists, psychologists, referral for relaxation or hypnotherapy, drug and alcohol problem treatment and referrals for support services including self-help groups, and community services.

The most frequent referrals were to physicians, surgeons, ophthalmologists, physiotherapists, dermatologists, orthopaedic, ENT, dietitian, O&G and other specialists in chronic physical condition encounters. Psychosocial referral was recorded in 0.1 per cent of chronic physical condition encounters and comprised two per cent of all referrals. In psychiatric encounters, a referral occurred in ten per cent of encounters, with four per cent for psychosocial interventions.

**The characteristics of chronic physical, psychological and co-morbid encounters**

The best model of characteristics of chronic physical, psychological, and overlapping chronic physical and psychological encounters compared to other encounters was
derived, using backwards and forwards stepwise logistic regression. Three logistic regression analysis were conducted with: (1) chronic physical disease encounter (without chronic psychological diagnoses) versus all other encounters as the outcome; (2) psychological diagnoses (without chronic physical disease) versus all others as the outcome, and (3) encounters with both chronic physical disease and chronic psychological diagnoses as outcomes. All patient and consultation characteristics were entered as possible explanatory characteristics (Table 5.9).

All three types of 'chronic' encounter were complex compared to other encounters, with a significant likelihood of multiple diagnoses.

Chronic physical encounters were more common in males and the elderly, while psychological encounters were more common in females. Psychological encounters with a chronic physical disease diagnosis were more commonly with older females. Psychological encounters without chronic physical disease were more common in consultations with younger women. Encounters at which a psychological diagnoses were reported were more likely to have a new problem managed, while those at which only a chronic physical disease was managed were not likely to have a new problem that is all problems were likely to be old problems.

Continuity was a strong predictor of an encounter at which a chronic physical diagnosis was managed. Three separate variables in the dataset referred to the issue of continuity. Each was shown to be independently predictive in the model for all chronic physical disease encounters. Specialist referral was also a strong predictor of all chronic physical encounter.

Physical support with (advice, counselling and health promotion with respect to drugs, lifestyle and treatment) and psychosocial support (counselling, emotional support reassurance and psychosocial referral) both were negatively predictive of chronic physical conditions in encounters (OR 0.83, p<0.0001) and (OR 0.44, p<0.0001) respectively. Including the prescription of psychotrophic drugs with the psychosocial variable, showed significant negative prediction of chronic physical encounters with or without psychosocial co-morbidity diagnosed in the encounter, while indicating a very high prediction in psychological encounters alone (see Table 5.9).
<table>
<thead>
<tr>
<th>Consultation characteristics</th>
<th>Predictors of chronic physical condition encounters</th>
<th>Predictors of overlap of chronic physical and psychological encounters</th>
<th>Predictors of psychological chronic condition encounters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice re drugs, lifestyle, treatment (0=no, 1=yes)</td>
<td>0.79 (0.73-0.85)</td>
<td>0.79 (0.73-0.85)</td>
<td>ns</td>
</tr>
<tr>
<td>Psychosocial support incl psych drug pres (0=no, 1=yes)</td>
<td>0.439 (0.39-0.47)</td>
<td>0.45 (0.42-0.48)</td>
<td>30.13 (26.69-34.00)</td>
</tr>
<tr>
<td>Medicare item (0=standard, 1=long/p prolong)</td>
<td>ns</td>
<td>ns</td>
<td>1.92 (1.69-2.15)</td>
</tr>
<tr>
<td>Specialist Referral (0=yes, 1=ycs)</td>
<td>1.12 (1.03-1.2)</td>
<td>1.17 (1.08-1.26)</td>
<td>0.68 (0.58-0.80)</td>
</tr>
<tr>
<td>Problem continuity (0=no, 1=yes)</td>
<td>2.87 (2.56-3.03)</td>
<td>0.39 (0.37-0.41)</td>
<td>0.83 (0.76-0.90)</td>
</tr>
<tr>
<td>Practice continuity (0=no, 1=yes)</td>
<td>1.33 (1.21-1.46)</td>
<td>1.22 (1.12-1.34)</td>
<td>ns</td>
</tr>
<tr>
<td>(GP advised follow-up) (0=no, 1=yes)</td>
<td>1.99 (1.89-2.09)</td>
<td>1.87 (1.78-1.97)</td>
<td>1.47 (1.34-1.65)</td>
</tr>
<tr>
<td>Sex (0=male), (1=female)</td>
<td>0.77 (0.74-0.80)</td>
<td>1.34 (1.29-1.40)</td>
<td>1.28 (1.19-1.39)</td>
</tr>
<tr>
<td>Age group (&lt;50 years)</td>
<td>1.60 (1.52-1.69)</td>
<td>2.38 (2.25-2.51)</td>
<td>0.84 (0.77-0.93)</td>
</tr>
<tr>
<td>(50-64 years)</td>
<td>2.06 (1.94-2.18)</td>
<td>2.06 (1.94-2.18)</td>
<td>0.52 (0.47-0.58)</td>
</tr>
<tr>
<td>(65+years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of diagnoses (1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 diagnoses</td>
<td>3.89 (3.70-4.08)</td>
<td>3.89 (3.7-4.0)</td>
<td>1.21 (1.01-1.03)</td>
</tr>
<tr>
<td>3 diagnoses</td>
<td>9.11 (8.49-9.77)</td>
<td>9.11 (8.49-9.77)</td>
<td>0.89 (0.76-1.03)</td>
</tr>
<tr>
<td>4 diagnoses</td>
<td>20.42 (17.29-23.52)</td>
<td>20.42 (17.72-23.54)</td>
<td>0.38 (0.29-0.49)</td>
</tr>
</tbody>
</table>

**Models of encounter types were also fitted with the psychosocial support variable excluding psychotrophic drugs. Odds ratios showed similar patterns.**

Table 5.9: Logistic regression models of factors best explaining the characteristics of chronic physical condition encounters and psychological encounters and their overlap in adult consultations**.

Source: Australian Morbidity and Treatment Survey Data from National Social Science Data Archives
Psychosocial support (excluding psychotrophic drug intervention) was an important predictor of psychological encounters (OR 14.1, p<0.0001), which increased to (OR 30, p<0.0001) when prescribing was included (see Table 5.9). Physical support, when entered into logistic regression in the place of psychological support had a similar magnitude of negative association with chronic physical disease in encounters (p<0.0001). The small overlap category of chronic physical and psychological encounters, were similar to the chronic physical encounters.

Both types of encounter were predicted by multiple diagnoses, high levels of practice and follow-up continuity, and specialist referral. The notable differences were that being female rather than male, being middle-aged rather than older, and having a new problem in the consultation were predictors of the overlap encounters. Psychological encounters were quite different. They were significantly more likely to be with those who were younger and female. They were characterised by having two or less diagnoses, less problem continuity, fewer specialist referrals (excluding psychiatrists) and being billed as longer.

**What sort of general practitioner provides chronic disease consultations?**

Table 5.10 reports the combined general practitioner and consultation characteristics associated with all chronic physical disease consultations without a psychosocial diagnosis. These were identified through logistic regression modelling of all consultation and general practitioner variables. Mid-career GPs, males, practitioners who either speak only English or less than 24 per cent non-English in consultations are likely to have chronic physical consultations. Such general practitioners were also less likely to have any post-graduate qualifications. The pattern of consultations did not change appreciably from that reported in Table 5.9. A similar picture of general practitioner characteristics emerged in the consultations dealing with chronic physical disease with a psychosocial diagnosis made in the same consultation, although postgraduate qualifications and consultation language were not explanatory factors. I did not report these findings in Table 5.10. However, general practitioners who documented psychological diagnoses without a chronic physical disease diagnosis in an encounter had quite different profiles to those diagnosing chronic physical disease. The differences are listed. The gender of the general practitioner was not explanatory. Practices were two to three general practitioners (OR 1.05 [CI 0.97-1.05]) or four plus general practitioners (OR 1.12 [CI 1.13-1.03]) versus solo. General practitioners were commonly Australian graduates and more likely to have a non-general practitioner postgraduate qualification (OR 1.79 [CI 1.62-1.98]). General practitioners who documented
providing counselling were more likely to be female (OR 0.9 [CI 0.81-1.0]) and were younger rather than older.

<table>
<thead>
<tr>
<th>GP and consultation characteristics of chronic physical disease encounters</th>
<th>Adjusted Odds ratio</th>
<th>Adjusted 95% confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GP characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP gender</td>
<td>1.26</td>
<td>1.19-1.33</td>
</tr>
<tr>
<td>(male vs female)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultation language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤24% non-English vs English</td>
<td>1.01</td>
<td>0.94-1.10</td>
</tr>
<tr>
<td>25-49% non-English vs English</td>
<td>0.79</td>
<td>0.67-0.92</td>
</tr>
<tr>
<td>50% non-English vs English</td>
<td>0.86</td>
<td>0.75-0.99</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-54yrs vs &lt;35yrs</td>
<td>1.01</td>
<td>0.93-1.09</td>
</tr>
<tr>
<td>≥55yrs vs &lt;35yrs</td>
<td>0.90</td>
<td>0.82-0.99</td>
</tr>
<tr>
<td>No of years in general practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5yrs vs &lt;2yrs</td>
<td>1.23</td>
<td>1.02-1.49</td>
</tr>
<tr>
<td>6-10yrs vs &lt;2yrs</td>
<td>1.38</td>
<td>1.14-1.66</td>
</tr>
<tr>
<td>&gt;10yrs vs &lt;2yrs</td>
<td>1.39</td>
<td>1.15-1.69</td>
</tr>
<tr>
<td>Place of graduation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asia, USA, Europe vs Australia</td>
<td>1.19</td>
<td>1.11-1.28</td>
</tr>
<tr>
<td>Africa vs Australia</td>
<td>0.95</td>
<td>0.89-1.00</td>
</tr>
<tr>
<td>GP post-graduate qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes vs no</td>
<td>0.95</td>
<td>0.90-1.01</td>
</tr>
<tr>
<td>Non-GP postgraduate qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes vs no</td>
<td>0.91</td>
<td>0.87-0.95</td>
</tr>
<tr>
<td>Consultation characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice re drugs, lifestyle, treatment</td>
<td>0.82</td>
<td>0.78-0.87</td>
</tr>
<tr>
<td>yes vs no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial support incl psych drug pres yes vs no</td>
<td>0.52</td>
<td>0.48-0.56</td>
</tr>
<tr>
<td>Specialist Referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes vs no</td>
<td>1.19</td>
<td>1.12-1.27</td>
</tr>
<tr>
<td>Problem continuity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0=no (any new problem in consult), 1=yes(all diagnoses are old problems)</td>
<td>0.43</td>
<td>0.41-0.45</td>
</tr>
<tr>
<td>Practice continuity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes vs no</td>
<td>1.16</td>
<td>1.06-1.27</td>
</tr>
<tr>
<td>Number of diagnoses (1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 diagnoses</td>
<td>3.35</td>
<td>3.07-3.67</td>
</tr>
<tr>
<td>3 diagnoses</td>
<td>6.94</td>
<td>6.52-7.39</td>
</tr>
<tr>
<td>4 diagnoses</td>
<td>14.04</td>
<td>12.44-15.85</td>
</tr>
<tr>
<td>(GP advised follow-up)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes vs no</td>
<td>0.55</td>
<td>0.53-0.57</td>
</tr>
<tr>
<td>Sex (female vs male)</td>
<td>0.76</td>
<td>0.73-0.79</td>
</tr>
<tr>
<td>Age group (&lt; 18 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(18-49 years)</td>
<td>1.61</td>
<td>1.48-1.74</td>
</tr>
<tr>
<td>(50-64 years)</td>
<td>3.30</td>
<td>3.04-3.58</td>
</tr>
<tr>
<td>(65-74)years</td>
<td>4.63</td>
<td>4.25-5.03</td>
</tr>
<tr>
<td>(75+)years</td>
<td>5.13</td>
<td>4.71-5.60</td>
</tr>
</tbody>
</table>

Table 5.10: Logistic regression model of GP and consultation factors best explaining the characteristics of chronic physical condition encounters in Australian general practice

Source: Australian Morbidity and Treatment Survey Data from National Social Science Data Archives
Discussion

Defining chronic physical and psychological conditions retrospectively is less than an exact process, particularly without either general practitioner or patient designation of duration or curability. However, given the size and representativeness of the dataset, the crude categories examined here are appropriate for the analysis of patterns of care reported.

In children's consultations, despite different classification systems, physical disease profiles recorded by primary care physicians are remarkably similar in the developed countries, where they have been studied. The AMTS data demonstrates a high prevalence of chronic disease diagnoses in childhood consultations: 15.7 per cent. Rates were similar to Dutch general practitioners morbidity data, with a prevalence of around 15 per cent (Knottnerus, Metsemakers and Limonard 1992), the United States of America, where community paediatricians recorded chronic disease in 15.6 per cent of children seen (Weiland, Pless and Roghmann 1992), and Sweden (Westbom and Kornfalt 1991). Primary care physician diagnoses in Australia, USA and Sweden indicate a similar-sized pool of chronic disease. However, population studies on which health and welfare services are likely to be based, varied markedly according to methods of case ascertainment and inclusivity (Westbom and Kornfalt 1987; Newacheck and Taylor 1992; Perrin et al. 1993). Asthma was the most common diagnosis accounting for approximately half the Australian cases. Despite somewhat higher rates of asthma diagnosis, Australian general practitioners appear to see a similar caseload to the US and Swedish physicians (Westbom and Kornfalt 1991; Weiland, Pless and Roghmann 1992). The main reason for attending a general practitioner was for the management of intercurrent acute common respiratory infections (ARI) followed by asthma management, obtaining a prescription and for immunisation. Specialist referral rates were higher than in non-chronic disease encounters, as expected. This is similar to Swedish patterns (Westbom and Kornfalt 1991).

The predominance of asthma, ARI and other acute common conditions in childhood chronic disease appear to shift general practitioner management towards episodic patterns of acute care, with immunisation as the major management activity not directly responding to acute disease recorded. Continuity of provider and setting are demonstrated. While longitudinal patterns of 'non-categorical' supportive psychosocial and physical care and case management cannot be interpreted in these cross-sectional data, some interesting questions are raised which require further study.

The literature points to a risk to the emotional, social and developmental well-being of the chronically ill-child (Siegel 1987; Stein and Jessop 1989; Newacheck and Taylor 1992; Weiland, Pless and Roghmann 1992; Westbom 1992; Jessop and Stein 1994). In
addition child and family psychosocial characteristics help to explain children’s health care use beyond traditional health and illness variables (Riley et al. 1993). Weiland, Pless and Roghmann (1992) identified behavioural and emotional patterns in children with and without chronic disease. Seven per cent in those with ‘serious conditions’ had emotional and behavioural problems in contrast to almost negligible rates in those with ‘minor’ or no chronic disease diagnosis. Those with serious disorders involving the central nervous system including epilepsy, had a prevalence of 15.5 per cent of mental disorders, the highest of any group. It was not possible to relate any specific type of mental health disturbance to specific chronic disease diagnoses, however, the impact of behavioural and physical disorders was judged by physicians to be more severe when a chronic physical illness was present.

Few AMTS chronic ‘serious’ disease encounters were recorded as having psychosocial diagnosis or care (intervention in the consultation or referral) in common with Weiland, Pless and Roghmann’s (1992) study. This is highlighted in Figure 5.2 which compares odds ratios for psychosocial intervention in chronic physical and psychological encounters.

Does this mean that Australian general practitioners like their American counterparts treat chronic conditions mainly using disease specific models? Does it suggest that such care is being managed outside general practice by specialists, hospitals or agencies? Or is it a reflection of the long-term nature of such ‘non-categorical’ care? Under-recording may explain a proportion of this phenomenon. Lau and colleagues (1982) found a greater likelihood of under reporting of diagnosis and management of psychosocial or rehabilitative problems than physical problems by medical practitioners. The current international glossary for general/family practice does not include definitions of psychosocial care (WONCA Classification Committee 1995. Encounters with younger or new patients with less continuity were more likely to have psychosocial care recorded, while ‘serious’ chronic conditions encounters with more continuity were less likely. This suggests that supportive care is more likely to be documented early in the problem or relationship.

Ongoing support through the doctor-patient relationship, longitudinal management in other consultations or perhaps familiarity in those who are well known and often seen may exist. Multiple diagnoses and psychosocial diagnoses however, predicted psychosocial intervention, independent of continuity status, indicating an intensity of need.
Psychosocial intervention recorded in chronic physical and psychological encounters

Figure 5.2 Psychosocial interventions in chronic physical and psychological consultations as documented by general practitioners in the Australian Morbidity and Treatment Survey.

Source: Australian Morbidity and Treatment Survey Data from National Social Science Data Archives

Statistical variations in general practitioner's documentation of psychosocial care exceeded those in other medical processes suggesting greater diversity among general practitioners in the recognition and provision 'non-categorical care'.

In adult and elderly consultations (18 years of age and over) chronic physical and psychological conditions constitute a considerable proportion of the workload of general practice. Although the top ten conditions cover around 60 per cent of chronic physical conditions, the remaining 40 per cent cover over 100 diagnoses. In contrast 15 diagnoses represent almost all psychological diagnoses, with anxiety and depression the most common accounting for around 80 per cent of diagnoses. Psychological problems were more common in chronic physical condition encounters (8.7%) compared to those without chronic physical conditions (6.11%).

The higher percentage in chronic physical encounters is in accordance with the literature where studies have shown that psychological problems were present in five to 20 per cent of those with chronic physical problems (Cassileth et al. 1984; Goldberg and Huxley 1992; Sullivan 1993).
The analysis by logistic regression suggested that management in chronic physical conditions was associated with low levels of psychosocial support when factors such as age, sex, continuity, Medicare item and number of diagnoses were taken into account (see Tables 5.5, 5.8 and 5.9). This pattern persisted in the adult encounters even when psychological problems are also managed in the same consultation, or psychotrophic drug prescriptions are included in the psychological support variable.

On the other hand, when general practitioners made a psychological diagnosis without a chronic physical diagnosis, they were highly likely to provide psychosocial support. Those with a psychological diagnosis alone were younger, had less co-morbidity, that is, fewer diagnoses and less practice continuity. There was a small, but statistically significant variation in supportive management in chronic physical and psychological encounters among general practitioners.

There are a number of plausible explanations for these observations, which bear further exploration in other research. The data are consistent with the interpretation that general practitioners work in a bimodal manner, providing both medical and supportive physical care and psychological support in chronic care. However, the distribution across consultations suggests that they predominantly adopt the acute care paradigm (disease-based) in chronic physical conditions and supportive-management in encounters with psychological diagnoses.

Perhaps more importantly, different types of general practitioners select and are selected by patients to treat different types of problems. Chronic physical disease encounters with or without psychosocial concomitant diagnoses are more likely to be conducted by mid-career males. These male general practitioners, who predominantly see male patients without documenting any psychosocial input, are unlikely to have general practice or other post-graduate qualifications. It appears that these general practitioners would be more likely to practise in the acute care and disease-based paradigm, that is also a more masculine model. The fact that counselling or any psychosocial or supportive input in consultations was more likely to be documented by females gives additional credence to this assertion.

The preference for and consistent application of the acute care paradigm by the bulk of general practitioners treating chronic physical disease is given further credibility by other evidence. There was a low level of support recorded when there are both chronic physical and psychological diagnoses in the same encounter with very little general practitioner variation in the process. This overlap group were female, older than the psychological diagnosis group, with more diagnoses and greater practice continuity.
A longitudinal rather than cross-sectional dataset is needed to test a range of several highly plausible explanations for these findings. Supportive care may be distributed over time and occur early or intermittently in consultations for someone with a chronic problem. While psychosocial and physical support both negatively correlate with problem continuity ($p<0.0001$), and general practitioner request for follow-up ($p<0.0001$) supporting this explanation; greater practice continuity is also associated with less supportive management ($p<0.0001$).

Familiarity may bring a lowering of patient expectations, routinisation or lack of interest in supportive management by general practitioners. Support may be incorporated into the doctor-patient relationship and not recognised by general practitioners in coding their consultations. Personal continuity in the doctor-patient relationship may provide the structure, but not necessarily all the functions of support for people with chronic disease when the focus is on physical conditions and the general practitioner is more comfortable in the acute care paradigm.

Another explanation is that people who attend general practitioners for chronic physical conditions do not have significant psychosocial and physical support needs. Finally, there is a possibility that general practitioners do not raise psychosocial and physical support issues because they do not have an adequate model for chronic care and there are not the facilities to support either general practitioners or patients outside the consulting room. Again, this is highly plausible.

The AMTs survey was done before the setting up of a supportive infrastructure in Divisions of General Practice, the flourishing of projects, the linking of resources, and the more recent focus on chronic care with the care-coordination trials. The recent emphasis on chronic care may also provide general practitioners with a language with which to codify intuitive supportive care.

Identifying the processes in chronic care should promote a more reflective approach and links with resources outside the consultation.
<table>
<thead>
<tr>
<th>Box 5.1 Examples of chronic conditions from ICPC listings from Dutch GP continuous morbidity recording</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typical Chronic disease/conditions from ICPC listings from Dutch GP continuous morbidity recording (Knottnerus, Metsemakers and Limonard 1992)</td>
</tr>
<tr>
<td>Psychological disorders: dementia, organic psychosis, schizophrenia, affective psychosis, anxiety disorder, hysterical disorder, depressive disorder, mental retardation, other unspecified psychosis, autism</td>
</tr>
<tr>
<td>Skin Disorders: atopic dermatitis/eczema, psoriasis, chronic ulcer</td>
</tr>
<tr>
<td>Sensory: retinopathy, macular degeneration, blindness, deafness</td>
</tr>
<tr>
<td>Cancer in all organ systems</td>
</tr>
<tr>
<td>Male genital: congenital anomalies urinary tract, nephrosis/glomerulonephritis</td>
</tr>
<tr>
<td>Neurological: Epilepsy, migraine, cluster headache, trigeminal neuralgia, polio, congenital anomalies, multiple sclerosis.</td>
</tr>
<tr>
<td>Musculoskeletal: congenital deformities, rheumatoid arthritis/allied conditions, acquired deformities</td>
</tr>
<tr>
<td>Respiratory: asthma, bronchiectasis, cystic fibrosis</td>
</tr>
<tr>
<td>Cardiovascular: congenital heart disease including pulmonary, heart failure</td>
</tr>
<tr>
<td>Endocrine: Thyroid-hyper or hypo, diabetes, other metabolic/endocrine/nutritional disease</td>
</tr>
<tr>
<td>Disability/impairment/handicap. Blood: hemoglobinopathies, chronic infections</td>
</tr>
</tbody>
</table>
Chapter 6

Characteristics of longer consultations in Australian general practice

Has Medicare enabled those with chronic disease or those at risk of chronic disease to achieve greater consultation length?

Abstract

Medicare billing patterns were modelled in relation to variables reflecting chronic disease care, psychosocial care and health promotion (greater patient need).

A retrospective analysis of Medicare billing data was conducted in the setting of Australian general practice from the introduction of Medicare (the universal system of fee-for-service with both private or direct [bulk-billing]) in 1984 until 1992.

The following data were analysed: (1) Medicare dataset, Australia from 1984-92 with 531 million general practice consultations; (2) Australian Morbidity and Treatment Survey (AMTS) dataset of 495 general practitioners providing 98,769 consultations 1990-91; and (3) the ACT Record Linkage Study (RLS) dataset of a sample of 555 ACT residents accessing 10,658 consultations 1988-92.

Consultations billed as ‘longer’ compared with those billed as ‘standard’. Patient need was represented by factors linked to worse health outcomes, collected in the AMTS and RLS datasets. Health factors included chronic diagnoses, health status and risk. Socio-demographic factors included education.

‘Longer’ consultations increased proportionally more than ‘standard’ in the national Medicare dataset between 1984-92. Logistic regression analysis described ‘longer’ consultations as bulk-billed rather than privately billed OR=1.74. General practitioners, in the AMTS, reported that ‘longer’ consultations dealt with psychological diagnoses OR=2.06 (1.83-2.32) or multiple problems OR (4 vs 1)=5.18 (4.31-6.22), but not chronic disease. Patients under 50 years of age, new to the practice, or with new problems had ‘longer’ consultations. In the RLS, those billed for ‘longer’ consultations were more commonly tertiary educated OR=1.99 (1.35-2.94), bulk-billed OR=2.75 (2.51-3.10) and middle-aged, but not overweight.

Variables representing chronic disease, other than psychosocial diagnoses, did not explain ‘longer’ consultations. The system of payment and greater educational advantage were dominant explanatory variables, although complicated by continuity and consultation characteristics including the number of problems managed.

These results support the argument that the current system of general practice organisation and remuneration does not encourage longer consultations for those with, or at greater risk of, chronic physical disease, particularly for those who are less educated and at greater disadvantage. It does appear to facilitate longer consultations for those with psychological problems, but not those accompanying chronic physical disease. However, prospective studies are needed to confirm this assertion.
Introduction

Medicare, the universal health-care system, was introduced in Australia in 1984. Despite an apparent increase in access to general practice consultations, differentials in health-care utilisation between the advantaged and the less advantaged persist (Deeble 1991). Although people with worse health, the older, and the less socially advantaged, have more frequent consultations per se, several analyses have begun to question whether the observed distributions are equitable. Deeble (1991) found that since the introduction of Medicare, overall there has been an inflation of services generally with little or no shift in the proportion accessed by those in poorer socio-economic areas. People with less socio-economic advantaged backgrounds, have worse risk of chronic disease, higher prevalence of chronic physical disease and fewer cultural resources than the more advantaged (Mackenbach, Stronks and Kunst 1989; Feinstein 1993; Mathers 1993). Weston (1996) found that despite poorer families and those with a member with chronic disease having more frequent Medicare general practitioner consultations, once the effect of having chronic disease was accounted for, these families actually had fewer than average consultations. Those who had relatively more consultations were more advantaged and took up more health promotion services such as dental checks (Weston 1996). In addition, United Kingdom studies suggest that those who are less educated and less advantaged are less able to access interpersonal equity and intersubjectivity with their general practitioner than more educated patients, leading to the formulation of Hart’s Inverse Care Law (Hart 1971; Cartwright and O’Brien 1976).

Consultation length has been found to indicate quality of care for people with chronic disease in the United Kingdom as discussed in Chapter 4. This has not been previously explored in Australia. We therefore, need to understand more about general practitioner consultations: their responsiveness to people with different status and health profiles, and how this relates to process, content and duration.

National data on timed general practitioner consultations are conspicuously absent, yet there is an abundance of billing data. Prior to November 1989, general practitioners billed for consultations on the basis of time. Then, the Commonwealth Government introduced vocational registration, with time and content (complexity) based descriptors for vocationally registered general practitioners. Consultation complexity is difficult to quantify and apparently medical practitioners still rely on duration as the yardstick for billing (Harris et al. 1996). The most common service provided is the ‘standard’ consultation that can vary from six minutes to 20 minutes for vocationally registered general practitioners and six minutes to 25 minutes for non-vocationally registered general practitioners. Consultations longer than this may be billed as long or prolonged consultations; those shorter than five minutes and less complex, are billed as a short consultation. In the United Kingdom, Howie (1997) found consultation outcomes such
as ‘enablement’ correlated with consultation duration. These outcomes correlated similarly with consultations divided into longer and shorter at various time points (including 15 minutes) (Howie, Heaney and Maxwell 1995). In Australia, Harris (1997) found a strong correlation between consultation billing and duration, although 20 per cent of longer consultations were underbilled (personal communication). However, as the study response rate was 58 per cent and consultations were videotaped, both the observed correlation and underbilling may not reflect typical practice (Harris et al. 1996). It is, however, a reasonable but untested assumption, that Australian general practitioner consultations divided into those billed as ‘longer’ compared to those billed as ‘standard’, reflect variations in actual consultation time. As no large Australian dataset contains both patient need and a comprehensive range of consultation characteristics, I investigated these issues in three datasets.

Methods

Medicare billing, patient need and consultation characteristics were analysed in three contemporaneous datasets:

1. Australian Medicare data, from the introduction of Medicare 1984 until 1992 obtained from the Health Insurance Commission;
2. the AMTS national general practice survey, 1990-91 (Bridges-Webb et al. 1992); and

These data respectively provide: longitudinal Australian and ACT billing trends; Australia-wide survey data from general practitioners documenting their consultations and billing; and ACT patient profiles linked to retrospective consultations over a seven-year period.

In all three datasets, consultation duration and billing was indicated by Medicare Benefits Schedule billing items. ‘Standard’ consultations (6 - <20 minutes) comprise billing item numbers 5, 23 and 53. ‘Longer’ (long or prolonged) consultations represent billing item numbers 7, 9, 36, 44, 54 and 57 (20+ minutes). These items represent ‘timed’ surgery attendances in regular hours. This approach excluded ‘after-hours’ surgery attendances, home and institution visits in order to describe routine care for an ambulatory population. For this analysis, I defined patient need as a predisposition to worse outcomes. Two groups of factors were used to indicate need: health factors, and socio-demographic factors in accordance with the principles of Andersen (1968) but measured differently in the AMTS and RLS data. Consultation characteristics were measured, but with different variables in these two datasets (Andersen 1968).
In the three datasets, I determined the probability of a 'longer' consultation versus a 'standard' consultation using logistic regression with methods varying according to the size and content of databases. Standard logistic regression was used with national Medicare data. Here, standard errors were ignored since these data represent all Australian general practitioner Medicare consultations for the period studied. With the AMTS and the RLS data, forward and backward stepwise procedures determined which variables to enter into a final model (using five per cent significance criterion). Individual general practitioners were likely to have similar types of patients and consultations in the AMTS and individual patients may have made variable numbers of visits to general practitioners in the RLS data. Therefore adjustment for clustering was made in these data. With the RLS data I used EGRET logistic regression with random effects procedure to adjust for clustering (EGRET 1993) The Generalised Estimating Equations (GEE) method, as implemented in SAS, provided logistic regression analysis adjusted for clustering in the larger AMTS database (SAS-Institute 1985; Liang and Zeger 1986).

Medicare Data—1984-92

A de-identified Health Insurance Commission Medicare dataset provided summary counts of 531 million consultations: all Medicare consultations 1984 to 1992. The dataset was restricted to consultation item numbers for each financial year from 1984/5 to 1991/2, with type of billing and State or Territory of patient residence.

The Australian Morbidity and Treatment Survey

The AMTS described 98,769 patient encounters of a random sample of Australian general practitioners during 1990-1991 (Bridges-Webb et al. 1992). A stratified national sample of 3.5 per cent of active general practitioners documented their consultations (See Appendix 1 for the Doctor Encounter Recording Instrument and Doctor Questionnaire). The following variables were selected for analysis including all health and socio-demographic factors. Health factors included: chronic physical disease, psychological and 'other' diagnoses and socio-demographic factors were: age and sex. Consultation characteristics were measured by: number of diagnoses; continuity (not presenting new problems, not being new to the practice and general practitioner requesting follow-up); and medical practitioner process (psychosocial care, health promotion and referral).

Psychosocial care included all psychosocial counselling, support, prescribing and referrals. Health promotion included all preventive, educative, and counselling activities related to drugs, treatment and life-style. Reasons for the encounter were excluded from the analysis because of collinearity with the number of diagnoses.
The ACT Record Linkage Study

The RLS study linked 1992 survey data of an ACT community sample of 555 residents with billing data on 10,658 ‘standard’ and ‘longer’ Medicare consultations, that the residents accessed over the previous five years (1988 to 1992) (McCallum, Lonergan and Raymond 1993). Patient need was represented by health factors: number of self-reported current health conditions, SF-36 measures and risk profiles (McCallum 1995). Risk profiles were: smoking; alcohol consumption; exercise status and body mass index. Socio-demographic need included: age; sex; ethnicity; family composition and contacts; social isolation and mobility; private health insurance; income level; occupational and employment status; and education level. Consultation characteristics were measured by: private or bulk-billing; whether weekday or weekend consultations and frequency or numbers of consultations in five years. The SF-36 scale measured the following health status domains: physical functioning; role limitations due to physical problems; social functioning; bodily pain; general mental health; role limitations due to emotional problems; vitality and general health perceptions (McCallum 1995). The SF-36 items analysed is described in the Patient Questionnaire in Appendix 2.3).

Results

Medicare data. Australian general practitioners billed 4.9 per cent of their 531 million consultations as ‘longer’ than ‘standard’ in the period from 1984 to 1992. In all States and Territories, the percentages of ‘longer’ consultations increased at a greater rate than ‘standard’ over time, almost doubling. The proportion of ‘longer’ consultations that were bulk-billed were persistently greater than those privately billed (see Figure 6.1). Consultations that were ‘longer’ and bulk-billed increased from 3.6 per cent to 7.4 per cent. Privately billed ‘longer’ consultations increased from 2.1 per cent to 4.7 per cent. The impact of vocational registration in 1989/90 appeared minimal, although the numbers of ‘longer’ consultations may have inflated slightly.

In the ACT, percentages of ‘longer’ privately billed consultations increased according to national trends. However, bulk-billed ‘longer’ consultations increased above national trends (4.5% to 10.4%). Logistic regression modelling demonstrated that the odds ratio of ‘longer’ consultations being bulk-billed versus privately billed (adjusted for year and State or Territory) was 1.74 nationally and 2.47 for the ACT.

The AMTS. General practitioners documented billing 6.4 per cent of their consultations as ‘longer’ than ‘standard’. Factors were identified associated with consultations billed as ‘longer’ compared with ‘standard’ using stepwise logistic regression. As clustering was negligible, this became the final model (see Table 6.1). General practitioners reported that ‘longer’ consultations dealt with psychological problems or multiple
problems per encounter. Characteristically, 'longer' consultations were with females, those under 50 years of age, or those presenting new problems, or being new to the practice. Specialist referrals and psychosocial care were more likely in 'longer' consultations. Health promotion although recorded infrequently, was less likely. Chronic disease diagnoses, with or without psychological co-morbidity, did not influence billed length.

The RLS. Overall, 6.7 per cent of consultations studied were 'longer' than 'standard'. Factors eliminated in the stepwise modelling, as having no effect on consultation duration, included: the number of self-reported health conditions, employment, all SF-36 measures, all health-risk factors and consultation frequency. Some factors lost significance when adjustment was made for clustering of visits by the same patient. These were notably sex OR (female vs male) = 1.31, 95% CI (0.96, 1.77) and social isolation OR (no isolation vs isolated) = 1.29, 95% CI (0.97, 1.71). Table 6.2 lists the factors that retained statistical significance at the five per cent level in the final model. 'Longer' consultations were more likely to be bulk-billed and conducted on weekdays. Well-educated, middle-aged, and not over-weight patients more commonly accessed such consultations.

Discussion

Patient need and the billing system: Australia-wide, in a study of 531 million general practitioner consultations (1984-92), the proportion billed as 'longer' increased. This increase occurred at the same time as a shift to bulk-billing and greater use of general practitioner services (Deeb 1991). Consultations of greater duration may provide better quality care for patients. This has been demonstrated in the United Kingdom, but less conclusively in Australia. Certainly, for patients with chronic physical disease, in my unpublished qualitative study of 110 consultations of 48 patients, those who accessed longer consultations had greatest opportunity to talk about their illness in the context of their life course. Illness narratives in the context of the life course have previously been identified as very important in the management of illness (Strauss and Glaser 1975). Those with longer consultations (greater than 20 minutes) also expressed greatest satisfaction with their general practitioner as a confidant (see Appendix 3).

Longer consultations, however, are generally less financially rewarding than shorter consultations for general practitioners under the Australian Medicare system. Greatest financial rewards accrue to those who have the greatest volume of standard consultations rather than a lesser volume of longer consultations in a given period (Dickinson and Doessel 1990).
Therefore, did bulk-billing and vocational registration promote greater access to ‘longer’ consultations, particularly for those who most needed it? Was the apparent increase because of ‘fee drift’ with a tendency to charge for a ‘longer’ consultation when the government pays directly? Conversely, are general practitioners more likely to reflect accurately their consultation processes in their billing when there is no direct cost to the patient? Harris and colleagues (1996) found a tendency to under-bill ‘longer’ (videotaped) consultations. However, it is not known whether underbilling is associated with bulk or private billing or patient characteristics. Have system changes ‘enabled’ the needy, but less-empowered or the most advantaged, to obtain consultation time? ACT residents appeared to achieve greater access to time or complexity through bulk-billing than the rest of Australia. Initially, the ACT, an advantaged population, had the lowest level of bulk-billing (44%), although the gap with respect to other States narrowed over time (Gilbert and White 1995). Within the ACT, the most educated (advantaged) accessed more ‘longer’ consultations.

In the AMTS, general practitioners documented that their response to psychological problems and multiple problems influenced billing for ‘longer’ consultations. The number of problems dealt with could, at least partially, represent general practitioner acquiescence to patient request rather than a response to patient need or symptom seriousness (Murrell et al. 1991). Provision of psychosocial care, but not chronic illness care nor health promotion, was associated with ‘longer’ consultations. According to the RLS, ACT general practitioners were more likely to bill middle-aged, rather than elderly or young, and non-obese patients for ‘longer’ consultations. Poor physical and mental health (SF-36) scores, social isolation and greater health risk did not influence billed length, whether consultations were bulk-billed or privately billed.

In the AMTS, ‘longer’ consultations were less likely with greater practice and problem continuity, with elderly patients or with those with chronic conditions. However, general practitioners requested more follow-up after ‘longer’ consultations. The AMTS did not record consultation frequency. In the RLS, consultation frequency was associated with greater need (McCallum, Lonergan and Raymond 1993), but did not influence access to ‘longer’ consultations. Do standard consultations adequately serve patients who are older, with chronic conditions, and greater continuity of care? It is likely that consultations provide complex physical, psychosocial or preventive care early and throughout the care continuum. General practitioners may reserve ‘longer’ consultations for those with acute or new problems or who request or command more time. However, familiarity engendered by longitudinal care, may mask unmet need, particularly, for health promotion and psychosocial care.
These major consultation datasets were the best that were available, but singly and collectively, inadequately depict relationships with patient need. Historical data, while providing important insights into time trends at low cost, limits the scope of the analysis. These data lack consultation outcomes, although RLS data links individual health profiles to retrospective consultation patterns. Also, the accuracy of reporting is unknown. For example, general practitioners might record the number of diagnoses more accurately in ‘longer’ consultations. Billing data is a crude proxy for actual timed consultations, particularly if the cut-off point is 20 minutes rather than ten minutes. This is further complicated by the addition of complexity to the billing descriptors of vocationally registered general practitioners in 1989. While the ACT population provides a relatively advantaged community for comparison with ‘average’ Australia, it also may reflect idiosyncrasies of local general practitioners and residents. However, a recently published Newcastle study found a significant association between higher occupational status and timed consultations longer than ten minutes (Wiggers and Sanson-Fisher 1997). This was similar to the association between education and ‘longer’ billed consultations in the ACT; education and occupational status both being markers of advantage.

Conclusions: Variables representing patient need, other than psychosocial, did not primarily determine consultation length. However, associations between ‘longer’ consultations and patient need are complicated by continuity of care and consultation characteristics including the number of problems managed. The system of payment appeared to be a dominant influence on billed ‘length’. This analysis cannot determine whether the current system of general practice meets the needs of those at greater risk of worse outcomes, but it raises questions about whether this is happening. The evidence suggests that Hart’s (1971) inverse care law may be operating, with older, sicker, and less-educated groups less likely to have longer consultations. We, therefore, need to understand more about the relationships between patient need, and supply and demand in the system of billing. We need to understand what factors modify general practitioner responses to patient health needs (eg. chronic disease, health risk) and socio-demographic characteristics. To do this will require prospectively designed studies that can more adequately explore the structure, process and outcomes of general practitioner care.
Figure 6.1: The proportion of 'longer' (than 'standard') Medicare GP services, bulk-billed and privately billed in Australia and the ACT 1984/5-1991/2 (531 million consultations). Source: Health Insurance Commission
<table>
<thead>
<tr>
<th>tables</th>
<th>text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socio-demographic factors</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>50-64 years vs &lt; 50 years</td>
<td>0.86(0.80-0.92)***</td>
</tr>
<tr>
<td>65+ years vs &lt; 50 years</td>
<td>0.81(0.74-0.88)***</td>
</tr>
<tr>
<td><strong>Sex (female vs male)</strong></td>
<td>1.07(1.01-1.03)*</td>
</tr>
<tr>
<td><strong>Health Need</strong></td>
<td></td>
</tr>
<tr>
<td>Psychological diagnosis, but without chronic condition diagnosed in encounter</td>
<td>2.06(1.83-2.32)***</td>
</tr>
<tr>
<td><strong>Consultation patterns</strong></td>
<td></td>
</tr>
<tr>
<td>Number of diagnoses</td>
<td></td>
</tr>
<tr>
<td>2 diagnoses vs 1 diagnosis</td>
<td>1.04(0.94-1.15)ns</td>
</tr>
<tr>
<td>3 diagnoses vs 1 diagnosis</td>
<td>3.14(2.75-3.59)**</td>
</tr>
<tr>
<td>4 diagnoses vs 1 diagnosis</td>
<td>5.18(4.31-6.22)**</td>
</tr>
<tr>
<td><strong>Continuity</strong></td>
<td></td>
</tr>
<tr>
<td>New problem in encounter vs all old problems</td>
<td>1.28(1.20-1.38)***</td>
</tr>
<tr>
<td>Practice continuity vs new to practice</td>
<td>0.46(0.39-0.54)***</td>
</tr>
<tr>
<td>Follow-up - GP advised vs not advised</td>
<td>1.95(1.79-2.13)***</td>
</tr>
<tr>
<td><strong>Doctor process</strong></td>
<td></td>
</tr>
<tr>
<td>Health promotion, education and advice re drugs, lifestyle, treatment</td>
<td>0.89(0.82-0.98)*</td>
</tr>
<tr>
<td>Psychosocial care with psychotropic drug prescription</td>
<td>1.40(1.28-1.53)***</td>
</tr>
<tr>
<td>Specialist Referral (excluding psychiatric)</td>
<td>1.60(1.47-1.56)***</td>
</tr>
<tr>
<td><strong>Significance levels</strong></td>
<td></td>
</tr>
<tr>
<td>p&lt;0.001; ** p&lt;0.01; * p&lt;0.05; ns p&gt;=0.05.</td>
<td></td>
</tr>
<tr>
<td>CI based on standard errors estimated with GEE adjusted for clustering of consultations with same doctor.</td>
<td></td>
</tr>
</tbody>
</table>

Table 6.1: Logistic regression model of billing for 'longer' vs 'standard' GP consultations. (n=98,769 patient encounters with 495 doctors) Source: The Australian Morbidity and Treatment Survey 1990-91

<table>
<thead>
<tr>
<th>tables</th>
<th>text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Characteristics predicting billing for longer versus standard consultations</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Socio-demographic factors</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>40-49 vs 20-39 years</td>
<td>1.67 (1.18-2.35)***</td>
</tr>
<tr>
<td>50-73 vs 20-39 years</td>
<td>1.34 (0.96-1.87)ns</td>
</tr>
<tr>
<td><strong>Years of education</strong></td>
<td></td>
</tr>
<tr>
<td>11-12 vs 0-10 yrs</td>
<td>1.06 (0.73-1.54)ns</td>
</tr>
<tr>
<td>13-14 vs 0-10 yrs</td>
<td>1.39 (0.89-2.17)ns</td>
</tr>
<tr>
<td>15-17 vs 0-10 yrs</td>
<td>1.99 (1.35-2.94)***</td>
</tr>
<tr>
<td><strong>Health problem or risk</strong></td>
<td></td>
</tr>
<tr>
<td>Body Mass Index 1989’ 15 to 44, obese = high</td>
<td>0.97(0.95-0.98)*</td>
</tr>
<tr>
<td><strong>Consultation patterns</strong></td>
<td></td>
</tr>
<tr>
<td>GP visit bulk-billed vs private billing</td>
<td>2.75 (2.51-3.10)***</td>
</tr>
<tr>
<td>GP visit on the weekend vs weekday</td>
<td>0.58 (0.39-0.88)**</td>
</tr>
<tr>
<td>**(mass(kg)/height(m))**2</td>
<td></td>
</tr>
<tr>
<td>Significance levels are indicated: *** p&lt;0.001; ** p&lt;0.01; * p&lt;0.05; ns p&gt;=0.05.</td>
<td></td>
</tr>
</tbody>
</table>

Table 6.2: Logistic regression model of billing for 'longer' vs 'standard' GP consultations. (555 patients with 10,658 consultations 1988-92).

Source: The ACT Record Linkage Study (RLS) 1988-92.
Part 2

What happens in practice

The Microlevel

People with chronic disease and illness attending general practice
Chapter 7

A study of general practice attenders

The journey of discovery lies not in seeking new landscapes, but in having new eyes.

Marcel Proust

Abstract

In this chapter, I begin an exploration of how people with chronic disease attending general practitioners understand and manage chronic illness and disease at an everyday and personal level.

General practice attenders with chronic physical disease were identified on the basis of their long-term medication use (being on repeat prescriptions). A purposive sample of 23 general practitioners in urban, rural and inner-city locations recruited 294 consecutive attenders, who were on repeat prescriptions for diagnoses that were medical and excluded major psychiatric conditions. They were surveyed about medical, treatment, and health (SF-36) status. Survey results were compared with those of 467 general practitioners recording 79,581 patient encounters, 42 chronic disease self-help group members from the ACT and 555 participants in an ACT community survey.

General practice attenders reported chronic disease profiles similar to those in consultations reported by general practitioners in the national survey with considerable specialist, hospital and medication usage. They reported significantly greater morbidity than the community sample in all SF-36 domains measured and described similar or worse morbidity than chronic disease self-help group members. Repeat prescriptions and six SF-36 domains appear to provide operational markers for chronic disease and morbidity.

Introduction

In Australia, there is very little understanding of the phenomenon of generic chronic illness care in general practice at the microlevel. Only two Australian studies have been published, (apart from work related to this thesis) that deal with generalist care of chronic illness at a personal level. Ward and colleagues (1994) identified that people with chronic disease and illness were the major group of persistent frequent attenders in Australian general practice. Winefield and Katsikitis’ (1987) and Winefield and Murrell’s (1992) studies of support identified that people viewed their general practice as a primary source of support when they were recovering from major hospitalisation for serious disease and described support processes in general practice consultations that related to quality of care. Most of the verbal interaction in consultations was related to information exchange in the forms of diagnosis and medical advice, and the rest to the relationship between the participants. Winefield and Katsikitis (1987) thus, characterised the doctor-patient verbal interaction in the consultation as a potential source of informational and emotional support for patients, with varying degrees of satisfaction for general practitioners and patients.
This section of the thesis, therefore aims to investigate further the management of ‘generic’ chronic illness and sick people in general practice incorporating the construct of support. It addresses the key question identified in previous sections, with a series of qualitative and quantitative studies. Is the evidence for an apparent lack of biopsychosocial (or supportive) chronic illness care identified at national level, collaborated or refuted by evidence obtained by a more detailed investigation at a microlevel? If this is the case, does it matter for people with chronic illness? What are the perceptions of general practitioners?

Repeat prescriptions and generic chronic disease

Repeat prescriptions were investigated as a ‘non-categorical’ or generic marker for chronic disease and the SF-36 measures as markers of morbidity and a proxy for chronic illness. Obtaining prescriptions was the third most common reason for encounter in chronic disease consultations in the AMTS survey (see Chapter 5). Being on a repeat prescription, thus, is likely be a marker for the cohort with chronic physical disease attending general practice. People must have a ‘disease diagnosis, a condition or a health problem’ of a long-term nature to be on long-term medication. ‘Repeat prescriptions’ are also common parlance for both general practitioners and patients. The utility of repeat prescriptions as a marker for chronic disease is investigated.

Identifying chronic illness using quantitative and qualitative approaches

The SF-36 health survey measures are valid and reliable indicators of self-reported health status. These have been widely validated and used in Australia and internationally (Ware and Kleinman 1992; McHorney, Ware and Raczek 1993; McCallum 1994). Self-reported poor(er) health status in response to a set of standardised questions should reflect chronic illness in a population, although it may not adequately represent the individual personal experience of their illness. For example, key SF-36 domains are self-rated health and mental health. Self-rated health is recognised as an independent predictor of mortality, above traditional risk factors (Idler, Kasl and Lemke 1990; McCallum, Shadbolt and Wang 1994). The Mental Health Index or the five psychological health items of the SF-36 is a well-validated screening instrument for psychological distress (or illness) comparable to the General Health Questionnaire (Cassileth et al. 1984). Relationships between ‘objective categorisation of subjective

---

1 The General Practice Evaluation Program of the Department of Health and Family Services funded this study “The management of chronic conditions in general practice”. I was principal investigator and designed and supervised the study execution. I was supported by my co-investigators Dr Jeanne Daly, Sociologist, Latrobe University and Professor R M Douglas, Director, The National Centre for Epidemiology and Population Health, Australian National University. This study provides the material for Chapters 7-11.
health status' of the SF-36 with 'understandings of illness' obtained through interviews, and ultimately to people's experiences, will be examined in as much as they address the study question, but not as a phenomenon. In order to complement the SF-36 in the identification of illness, I developed the Impact of Illness Scale (IIS) using grounded theory principles to discern people's perception of outcomes of having chronic illness. Chapter 8 thematically analyses the experiences of illness as revealed through interviews. The nature of and response to illness is the subject of ongoing analysis with the study data, and is discussed in relationship to social support and transdisciplinarity in Chapter 12. It is a huge topic that this thesis cannot adequately address and requires more research. For the purposes of the quantitative study, it is assumed that Self-Rated Health, the Mental Health Index, and the IIS (social constructions of researchers) identify dimensions or outcomes of having chronic illness (personal constructions of afflicted individuals).

Aims

The aims of the whole study were to produce an in-depth understanding of the management of chronic disease and illness in typical general practice attenders. This was in order to describe their physical and psychological profiles and their experiences, needs, and satisfaction with respect to disease, illness and general practice care. I sought to identify non-categorical indicators of chronic disease and illness that were robust, easily accessed, highly prevalent and broad enough to warrant the term 'generic'. Equally important for this understanding were general practitioners' experiences and perceptions of chronic illness and disease care.

The specific questions that this chapter addresses are: do repeat prescriptions adequately identify those with chronic physical conditions in general practice and with significant morbidity? How is illness constructed by people on repeat prescriptions?

Methods: Common to Chapters 7, 8, 9, 10 and 11

Selecting general practitioners

Twenty-three general practitioners were purposively selected to represent three diverse geographic locations: rural, urban and inner-city, and four types of practice setting: single and group practice, and small and large community health centres. My initial plan to use a random sample of general practitioners did not produce a good geographical mix of practice and GP types. I then decided to use key informants, that is, I consulted senior general practitioners in the three locations about who might be interested in such a study, and were located in areas with reasonable numbers of chronic disease patients. A list of 46 names was compiled from key informants based on the yellow pages of the telephone index. The 23 general practitioners who were selected and participated in the
study over represented the educators or teachers of general practice. It is in this group, however, that one would expect to find 'high-quality' practice for the local area. Extended-hours clinics in both Melbourne and Canberra refused participation. However, all general practitioners in the rural town and its satellites participated, giving population coverage (See Appendix 2.1 for GP study information).

Selecting people on long-term repeat prescriptions - the survey

From their appointment list on the day of pre-arranged visits by a research assistant, participating general practitioners identified consecutive attenders who were known to be on repeat prescriptions for medical problems, for 12 months or longer. They were asked to exclude those with primary psychiatric problems and who did not speak English. Two hundred and ninety-four general practice attenders of the 23 general practitioners were systematically selected and asked to complete questionnaires with assistance in the surgeries. Only adults, those 18 years and over, were recruited (See Appendix 2.3 for selection protocol. Appendix 2.2 provides different selection protocol for qualitative study reported in Chapters 8, 10 and 11).

The selection and exclusion criteria reflect the focus of the thesis described in Chapter 1. I elected to study (non-conflictual) chronic physical disease without primary psychological morbidity such as schizophrenia, serious depressive illness or Alzheimer’s disease, in order to detect the impact of physical conditions on psychological well-being. To more clearly identify the psychological burden that chronic physical disease brought and how the study general practitioners responded, general practitioners were asked to exclude people with primary psychiatric problems. This was to explore the apparent duality of care identified in Chapters 5 and 6, where people with a psychological diagnosis alone were given 'psychological interventions' but those with chronic physical disease and a psychological diagnosis were managed similarly to other chronic physical disease consultations. People who spoke English were selected because of convenience. The study funds did not stretch to interpreters. It seemed highly likely that non-English speakers would have even greater needs in illness, than the English speakers due to communication problems (Weston 1996). The patient response rate was 85 per cent; the general practitioner response rate was 50 per cent.

Self-help group members were recruited by the investigator attending self-help group meetings. I approached four 'mainstream' chronic physical disease self-help groups who agreed to invite members to a special meeting to discuss chronic illness care in general practice as described in Chapter 1. The self-help group members who attended the meetings described themselves as core members who actively ran their organisation, or as those who were in a crisis of diagnosis or treatment or experiencing threat to life or function or personal problems. The majority of members, in comparison, were described
by the focus group participants as those who received the newsletter, more likely to have stable conditions, and did not participate in the active processes of the group. Questionnaires were distributed at the meeting and through the next newsletter. Around 400 questionnaires were distributed and only 42 responses were received. These were predominantly those attending the meetings.

In order to describe how my purposively selected sample of general practitioners and their attenders compared with population-based samples, I identified a series of other studies that would provide appropriate ‘normative’ data. All the quantitative datasets used in the study are described in Box 7.1. All data studied relates to survey respondents recruited in the time period 1992-3.

**Box 7.1: Sources of quantitative data for Chapters 7 and 9.**

**Quantitative study survey respondents recruited in 1992-3**

Survey of GP attenders on repeat prescriptions:
- 97 Rural NSW patients of 6 GPs in 2 two-GP practices and 2 single-handed practices. The GPs represented all the practices in the area and were all male.
- 144 Urban Canberra patients of 12 GPs; 1 in single-handed practice, 2 single-handed but with assistants and 9 GPs were from 4 community health centres, though 3 left for private practice during the study. Six of the GPs were male and 6 were female.
- 53 Inner city Melbourne patients of 5 GPs; 1 GP from a large group practice, 1 GP in a single handed practice, 3 GPs from larger community health centre. Four of the GPs were female, 1 male.

Comparative data was obtained from survey of:
- 42 Self-Help Group members were from the Epilepsy Association of the ACT, the ACT Cancer Society, the Asthma Association of the ACT and the Non-insulin dependent diabetes Self-Help group of Diabetes Australia, Canberra. The investigator distributed questionnaires at routine meetings (almost 100% response) and through newsletters (very low response-5%).

Comparative retrospective data was obtained from surveys of:
- 555 participants of a population based survey of the ACT provided normative data for the SF-36 from the NCEPH record linkage data-set in 1992 (McCallum, Lonergan and Raymond 1993).
- 467 Australian general practitioners (a random sample) documenting 79,581 patient encounters in those 18 years and older during 1990-1991 from Australian Morbidity and Treatment Survey data-set accessed through the National Social Science Data Archives (Bridges-Webb et al. 1992).

**Questionnaire for general practice attenders on repeat prescriptions**

The content of the questionnaire was derived from a synthesis of a preliminary literature review, a series of interviews, and focus groups with patients, general practitioners and academics, reported previously. The questionnaire consisted of questions on socio-demographics, medical conditions and medication, health care, and the items of the SF-36 that were common to the SF-20 (Medical Outcomes Study health questionnaire) and scales developed during the study from focus groups and interviews about illness impact, expectations / needs and experiences of general practice care.
Mental health, self-rated health, physical function, pain, limitation of social functioning by illness, role function that reflected quality of life and coping with chronic illness, and self-rated health were measured using the validated SF-36 (Ware and Sherbourne 1992). It is a well-validated instrument in the United States of America (McHorney et al. 1994; Ware 1994), the United Kingdom (Brazier et al. 1992) and Australia (McCallum 1995). I analysed the six items which were common to the SF-20 and the SF-36 version that had been validated in the ACT (McCallum, Lonergan and Raymond 1993). Medical conditions were self-reported by participants completing the questionnaire, but with assistance from research assistants in the surgery. The same ICPC codes were then used to categorise these conditions that were subsequently coded by the research assistants (Lamberts and Woods 1987). (See Appendix 2.2 for Questionnaire).

**Scale development**

In addition, I used a grounded theory approach to develop three scales for the survey:

- **Illness Impact Scale**: a scale of impact of health conditions upon people's lives (personal outcomes) eg. finances, family, work, and a sense of control over health;

- **Felt Need**: a scale of expectations, rating the importance of general practice qualities and care that was refined into 3 scales of clinical, personal and structural needs; and

- **Dissatisfaction** based on **Met Need**: a scale rating quality of current general practice management, ie lack of satisfaction.

Chapter 9 reports on the development and testing of scales. Items were factor analysed and the scales demonstrated good internal reliability. I also developed scales of the extent to which conditions were life-threatening and disabling. Life-threatening and disabling were rated separately on a three-point scale. The three points were: unlikely to be life-threatening or disabling; may be or potentially life-threatening or disabling; and likely to be life-threatening or disabling. I interrogated the first two pages of the questionnaire, without the SF-36 or other measures of morbidity, as 'clinical casenotes'. I used clinical judgement and applied my general practice skills to classify people's medical conditions and health service use profiles into those six groupings.

Box 7.2 lists all raw and composite variables from the survey that I will analyse in this thesis. It also describes the conceptual model on which I based the survey. Global illness impact and self-assessed health status represent quantitative measures of illness. General practice care is characterised by patient perceived met and felt needs for such care, as well as patterns of usage recalled over the past 12 months. Patients were also asked about the type, size and frequency of other health care accessed in the past 12 months.
Finally, I asked patients to describe themselves in terms of their biopsychosocial characteristics and their disease and illness profiles.

<table>
<thead>
<tr>
<th>Box 7.2: Variables and conceptual model for the Survey of GP attenders on Repeat Prescriptions used in quantitative analyses in Chapters 7 and 9</th>
</tr>
</thead>
</table>

**ILLNESS IMPACT SCALE**

**HEALTH STATUS (SF-36)**
- Mental Health, Self-Rated Health, Physical Function, Pain, Social limitation due to Illness, Role Function

**GP CARE IN THE PAST 12 MONTHS**
- *M*et need Scale: Dissatisfaction
  - Needs, wants, expectations of GP care
  - Felt need Scales
  - Biomedical and technical skills
  - Support functions in the doctor-patient relationship
  - Supportive practice structure including care coordination and access

**GP Care Profile**
- Number of GP visits in the past 12 months
- Number of GPs consulted in the past 12 months
- GP and practice continuity in the past 12 months
- Practice stability - ie main doctor was in the practice for the past 2 years
- Main GP- gender, whether in community health centre or private practice

**HEALTH CARE NETWORK IN THE PAST 12 MONTHS**
- *S*ize
  - Specialist - number consulted in the past 12 months
  - Allied Health Professionals number and type - physical or psychosocial in the past 12 months
  - Alternative, other practitioners and self-help groups number seen in the past 12 months

- *F*requency of visits
  - Number of specialist, allied health, other health related consultations in the past 12 months

**BIOPSYCHOSOCIAL CHARACTERISTICS OF INDIVIDUALS**
- Diagnostic and Non-categorical markers of disease(s)
  - Diagnoses up to 8
  - Number of medical conditions, Number of repeat prescriptions
  - Time since diagnosis of oldest and newest medical problem,
  - Medical condition(s) life-threatening or disabling rating by Martin

- Socio-demographic factors
  - Age, Gender, Living arrangements, Occupational group,
  - Doctor location: rural NSW, urban ACT, inner-city Melbourne

**Statistical approach and methods**

The aim of the quantitative analysis is to identify patterns in patient self-report data and refine these patterns into a meaningful understanding of chronic illness experiences and clinical care. I judged that the variables to be analysed in this thesis, such as perceptions, states of health, numbers of medical conditions are discrete, nominal or 'qualitative' rather than continuous. Thus, the statistical approaches used in this thesis are
predominantly categorical. Statistical tests are used to indicate the magnitude of
association rather than population inference. In the derivation of scales and their factor
analysis, continuous techniques are used. However, in the analysis the scores are
grouped into broad categories in order that undue statistical precision will not be
inferred from 'pseudocontinuous' data. Therefore, the types of analyses used are
categorical or non-parametric. Techniques include: two-way or multi-way contingency
tables; non-parametric correlations; chi-square tests; Mann Whitney-U tests; factor
analysis and loglinear models. Two types of summative techniques were used:
hierarchical loglinear modelling and logistic regression. Because this is cross-sectional
data, there is essentially no way of truly identifying the 'outcomes' of care. A more
appropriate approach is in the identification of complex patterns associated with those
reporting worse outcomes, such as greater morbidity or illness impact. Hierarchical
loglinear models are like a multivariate extension to a chi-square test on a two-way
cross classification table. They identify which categorical variables are related to one
another by assessing the relative counts of observations in a multiway contingency table.
No causality is involved, since no particular variable assumes the status of an outcome
variable. This is useful if there may be many variables related to one another. On the
other hand logistic regression was also used because it was considered necessary to
focus upon particular relationships where an outcome was clearly discernible. Specific
factors may influence dissatisfaction. Thus, possible explanatory factors were entered
into a logistic regression model to determine factors predicting worse outcomes; in
Chapter 9 Met Needs (Dissatisfaction) and Felt Need for general practice care. Strictly
speaking, there are no real outcomes because the study is neither experimental nor
observational over time. However, both dissatisfaction and worse illness or morbidity
are patient states or 'outcome' of a complex interplay of clinical care, disease and
personal context. Therefore, hierarchical loglinear models were derived from all
variables at every level plus the 'outcome' in order to determine significant interactions
or patterns among these variables. In order to determine the most significant
interactions, a summative logistic regression analysis with the outcome as the dependent
variable, and the significant interaction variables and terms as explanatory variables,
was conducted.

Clustering

Because patients were selected in different locations through different types of practice,
and as attenders of different types of general practice, there was a high likelihood of
clustering. Interestingly, the effect of clustering around different general practitioners
although adjusted for, was not statistically significant in the analysis of the AMTS in
Chapter 5. Although much more complex analysis was performed in anticipation that
intra-cluster correlations would be high, in fact they were low (see Chapters 5 and 6). In
order to avoid unnecessary analysis on this smaller dataset, intracluster correlations were
conducted in advance on several key variables to determine whether random effects analyses were necessary. Using binomial estimating equations on the SPIDA statistical package, intracluster correlations of age, patient sex, location and doctor sex in relation to both illness impact scores and living arrangements were determined. Estimates of common correlation were found to be $< 0.039$ (in practical terms negligible) with correlation coefficients that did not reach 0.05 levels of significance. The only correlation that came close to significance was age group with living arrangements ($p=0.056$). Therefore, it was judged unnecessary to adjust for clustering in these data.

**Variable selection and groupings**

Variables are grouped under the conceptual levels and sublevels described in Box 7.2. For each analysis either some or all of the variable groupings either at a conceptual or sublevel were entered into the analysis, according to the question being addressed. For example, the SF-36 measures may be individually linked with general practice satisfaction and some disease markers in some models or in the summative logistic regression models. Each conceptual level may be entered sequentially with all variables under each conceptual heading entered en bloc in a stepwise manner. In each table, there will be a description of the levels and groups of variables entered into the model. If what is entered is composite or derivative, the mechanism for this will be indicated.

**Methodological considerations and limitations: quantitative and qualitative**

The purposive approach to sampling of general practitioners through peer networks, was chosen for two reasons.

First, the study sought to examine what was likely to be ‘good practice’ in the three major locations of Australian general practice. Given the resource constraints, a ‘random sample’ would not efficiently select ‘good’ general practitioners in practices that had appropriate proportions of people with chronic disease.

Secondly, an initial pilot study revealed that, at the time, only certain types of general practitioners felt comfortable with, or were willing to participate, in such an intensive study. Again these were more likely to be teachers, educators or opinion leaders. Whether the group selected are ‘good general practitioners’ cannot be answered by the study, but they are likely to exert a significant influence upon the practice of future general practitioners.

In Australia, the definition of ‘quality’ in general practice care is currently under review. Three leading international general practice academics in the United Kingdom, Canada and the United States of America all conclude that ‘quality’ in chronic disease care is
dealing with contextual concerns, medical and psychosocial co-morbidity, both illness and disease, and responding to facts, fears, and feelings (Waitzkin, Britt and Williams 1994; McWhinney 1996; Howie 1997). Also, the study is not an evaluation judging outcomes or performance, rather it is an exploration of frameworks and experiences of care. The purposive sampling of general practitioners is also justified because (1) small numbers were involved and no statistical calculations were conducted on general practice responses, and (2) representativeness of different practice types in three different localities was required. In addition, the pilot testing indicated that even in similar geographic areas, chronic disease patients were congregated around certain general practitioners in certain practices.

The general practice selection of attenders both biases participants towards frequent attenders who were more likely to be satisfied (a positive or negative bias) and towards a sicker cohort (a positive bias), but who were also well-known to the general practitioner (Ward et al. 1994). The survey questionnaires were anonymous to facilitate openness of expression and to free people from the constraints of the power relationship between them and their general practitioner. In the interviews and questionnaires, ‘wanting to please’ may have limited true expressions of feelings and experiences. This is known variously as social desirability, courtesy or obsequiousness bias (Bowling 1995).

In the interviews, people did discuss negative aspects of their care, however, this was particularly related to medical practitioners other than the current general practitioner. This issue is discussed later in some detail. Another method of checking bias was the inclusion of respondents from self-help groups where there was no possible association with their general practitioner. However, self-help group members may differ in other ways from ‘typical general practice attenders’ or the wider population of people with chronic disease. On the other hand, people with chronic disease are highly likely to attend general practice. People with chronic medical conditions typically are ‘tied’ to general practice for their care; at a minimal level for ongoing repeat prescriptions. For example, in the 1989-90 National Health Survey, 16.2 per cent of the population with self-reported diabetes or high blood sugar attended a medical professional in the previous two weeks. Of these, 84.6 per cent consulted a general practitioner at the most recent visit, at higher rates than other professionals (ABS 1991).

The disadvantage of an anonymous questionnaire was that it is not possible to say whether non-responders differed from responders in a systematic way. The advantage of this study methodology was the ability to explore such perceptions through interviews and field work. Two common, but opposing views of the general practitioners were that ‘only those who felt grateful would want to participate in the study,’ or those who were...
'disgruntled were given an opportunity to complain anonymously.' Reports from research assistants’ field work were that the main themes around non-response, were that patients felt it an imposition that outsiders should come in and ask them to expose their own private lives or subject their general practitioner (with whom they were very satisfied) to possibly hostile scrutiny, particularly in the one rural practice and one community health centre. Other themes were ‘to protect their general practice being scrutinised by the government’. In one rural practice all patients of the senior partner refused because they (and or the receptionists) felt invaded with lots of surveys and considered that their general practitioner (who was willing to participate and was interviewed) should not be investigated. Most other non-respondents were too ill or felt too busy. Also a small proportion (around five percent of both quantitative and qualitative samples) were not approached at all as receptionists indicated that patients were too ill, upset or too busy.

While the many methodological limitations discussed apply to an epidemiological study, because this is an exploratory study, they are less important in interpreting the results.

Results of the survey of general practice attenders on repeat prescriptions

Disease and health-care profiles of general practice attenders on repeat prescriptions

General practice attenders in receipt of repeat prescriptions reported a diverse range of greater than 100 conditions; in addition to the ‘typical’ chronic conditions. The most common diagnoses reported by general practice attenders (excluding those recruited through self-help groups) were: hypertension (36%), osteoarthritis (25%), ischaemic heart disease (15%), asthma (15%), diabetes (13%) and gastric-duodenal ulcers (12.5%).

Menopausal problems were reported by three per cent of the sample. Questionnaires of respondents not on repeat prescriptions for medical problems or for contraception were negligible. These patients and those on hormone replacement therapy alone, although three per cent of the total, were excluded from further analyses.

The majority reported multiple conditions. The most common conditions diagnosed in the repeat prescriptions group and the national AMTS sample (Martin and Nisa 1996) are described in Table 7.1. Psychiatric or psychological diagnosis was reported by six per cent of the repeat prescription group compared with general practitioners recording of 8.7 per cent in the AMTS consultations (albeit with no exclusion of those with primary psychological problems).
Most Common Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>GP attenders on repeat prescriptions self-reported morbidity profile</th>
<th>GP recorded problems managed in a cross-section of consultations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percentages</td>
<td>Percentages</td>
</tr>
<tr>
<td>Hypertension</td>
<td>36</td>
<td>23</td>
</tr>
<tr>
<td>Ischaemic heart disease*</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Osteoarthritis**</td>
<td>25</td>
<td>8</td>
</tr>
<tr>
<td>Asthma</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Diabetes</td>
<td>13</td>
<td>5</td>
</tr>
</tbody>
</table>

*Ischaemic heart disease represented several ICPC codes including angina and heart failure
**Osteoarthritis also represented a combination of codes including generalised osteoarthritis, osteoarthritis of the hip, spine etc.

Table 7.1. Five most common conditions reported by 294 patients on repeat prescriptions, who were consecutive attenders of 23 GPs and a national cross-sectional sample of 467 GPs documenting 79,581 patient encounters (problems managed) coded post hoc using a chronic condition list.

Forty-seven per cent of the total group reported three or more medical problems of an ongoing nature. Sixty-six per cent had life-threatening or potentially life-threatening conditions and a similar proportion had disabling conditions. Chronic health problems were not confined to the elderly as is often assumed. In the rural practices that treated the whole population in the township and surrounds, the age distribution of attenders on repeat prescriptions was 18-50 (28%), 51-65 (26%) and >65 (46%). Table 7.2 reports the profiles of general practice attenders in the three study locations: rural New South Wales, urban ACT, and inner-city Melbourne. Self-help group members provide a contrast.

Repeat prescriptions

Twenty-eight per cent of the general practice attender group were in receipt of repeat prescription for one drug, 24 per cent for two drugs, 33 per cent for three-to-four drugs and 15 per cent for more than four drugs. The maximum was for eight drugs. The number of repeat prescriptions was not significantly different among the general practice attender groups, although the general practice attenders had more prescriptions than the self-help group members. While the practice attenders reported more medical conditions overall, than the self-help group, the Melbourne group had the greatest number of diagnoses (see Table 7.2).

Demographic profiles

General practice attenders on repeat prescriptions were heterogeneous with a wide spread of ages, social class, occupational groups and living arrangements. Socio-
demographic and health-care characteristics in rural, ACT and Melbourne attenders, the self-help groups, are described in Table 7.2. There were significant differences in age, gender, occupational class and living arrangements, and number and type of medical conditions, investigation rates and operations across the groups identified using a chi-square test.

Marital status was analysed demonstrating significant differences amongst the groups, but was not described in Table 7.2 because it was very similar to living arrangements. Rural and ACT attenders were similar in age, marital and social status profiles. The ACT had a larger professional class and clerical class, and more living alone particularly, than inner-city Melbourne. Rural New South Wales had farmers and graziers rather than professionals and bureaucrats in the upper occupational groups and shearsers and tradesmen in the middle groups rather than public servants The self-help group members were younger, predominantly middle-class and few lived alone. The Melbourne group were mainly factory workers or housewives. They were older, living as a couple or with a family. A high percentage were not born in Australia (not reported in Table 7.2).

Patterns of service use

Different patterns of general practice attendance emerged. The Melbourne attenders and self-help group members were more likely to see multiple general practitioners in the past 12 months. Melbourne had the highest number of self-reported general practice visits and specialist consultations. The ACT and rural attenders indicated similar patterns of general practice use. The rural group, however, reported the fewest specialist attendances.

Twenty-five per cent of the total group had one or more hospital admission, and 30 per cent had one or more operations or procedures in the past 12 months (see Table 7.2). While there was almost a significant difference in hospitalisation rates, there was no difference in distribution of the number of prescription drugs among the general practice attender group.

The use of allied health professionals, alternative practitioners and self-help groups were very low in all groups. Patients attending community health centre doctors were slightly more likely to attend self-help groups than others, but actual rates of attendance of a self-help group in general practice attenders’ sample were very low (less than one per cent). The self-help group members described similar admission profiles, but differed in that they reported fewer repeat prescriptions, fewer diagnoses, and fewer general practice attendances than the attender group.
Morbidity or illness burden: the SF-36

The SF-36 scores among general practice attenders demonstrated similar patterns but with some differences between locations. Figure 7.1 presents the patterns of average raw scores for each of the six scores analysed by location in those under 65 years of age and those 65 years of age and over. The Kruskal-Wallis non-parametric test for differences in rank scores within each age group, identified those domains which showed significant variation among the three locations.

In the under 65 age group, mental health and role function show significant variation while self-rated health, pain, social limitations due to illness, and physical function did not.

In the 65 year and older group, self-rated health, pain, social limitations due to illness, and physical function due to illness, showed significant variation. (Significant variation was judged to exist if rank scores differed at p <0.05 level of significance.)

Overall, the general practice attenders had similar SF-36 mean scores compared with the self-help group members and worse than the ACT community sample reported in Tables 7.3 and 7.4. Of general practice attenders, 52 per cent reported fair to poor self-rated health. Twenty-six per cent of self-help group members reported fair to poor self-rated health. Pain and physical function were also significantly worse in the general practice attenders: 39 per cent reported moderate pain and 29 per cent severe to very severe pain in the past four weeks. In self-help group members, 14 per cent reported moderate pain and nine per cent severe pain.

Mental health scores were similar in general practice attenders and self-help groups overall, but with worse scores in Melbourne attenders. Illness limitations of social function and role were considerably better in self-help group members.

Table 7.3 reports a breakdown of the mean SF-36 scores by age and sex of general practice attenders and the ACT self-help group member sample. Scores were compared using the Mann-Whitney-U test and the differences between the two groups for each age and group were reported. Age was divided into two groups, at 65 years, however the numbers in the older age group were very small.
<table>
<thead>
<tr>
<th>Gender</th>
<th>Rural NSW n=97 No. (%)</th>
<th>Urban ACT n=144 No. (%)</th>
<th>Inner Melbourne n=53 No. (%)</th>
<th>Total GP attender group n=294 Percentages</th>
<th>Self-help group members n=42 Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>45(46)</td>
<td>57(40)</td>
<td>13(25)</td>
<td>38</td>
<td>38</td>
</tr>
<tr>
<td>Female</td>
<td>52(54)</td>
<td>87(60)</td>
<td>40(75)</td>
<td>72</td>
<td>72</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-50</td>
<td>27(28)</td>
<td>32(22)</td>
<td>5(9)</td>
<td>22</td>
<td>69*</td>
</tr>
<tr>
<td>51-65</td>
<td>25(26)</td>
<td>55(38)</td>
<td>21(40)</td>
<td>34</td>
<td>21</td>
</tr>
<tr>
<td>66+</td>
<td>45(46)</td>
<td>57(40)</td>
<td>27(51)</td>
<td>44</td>
<td>10</td>
</tr>
<tr>
<td>Occupational Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White collar</td>
<td>44(48)</td>
<td>79(61)</td>
<td>-</td>
<td>48</td>
<td>61*</td>
</tr>
<tr>
<td>Blue collar</td>
<td>11(12)</td>
<td>16(12)</td>
<td>12(23)</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3(3)</td>
<td>2(2)</td>
<td>6(10)</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Home duties</td>
<td>32(35)</td>
<td>30(23)</td>
<td>20(38)</td>
<td>26</td>
<td>9</td>
</tr>
<tr>
<td>Living Arrangements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone or with unrelated</td>
<td>33(34)</td>
<td>55(42)</td>
<td>8(15)</td>
<td>35</td>
<td>12*</td>
</tr>
<tr>
<td>As a couple</td>
<td>47(48)</td>
<td>64(49)</td>
<td>38(72)</td>
<td>53</td>
<td>57</td>
</tr>
<tr>
<td>Other family</td>
<td>17(18)</td>
<td>12(9)</td>
<td>7(13)</td>
<td>14</td>
<td>31</td>
</tr>
<tr>
<td>No. of Repeat Prescriptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>22(24)</td>
<td>40(30)</td>
<td>14(26)</td>
<td>28</td>
<td>42*</td>
</tr>
<tr>
<td>2</td>
<td>18(19)</td>
<td>34(25)</td>
<td>16(30)</td>
<td>24</td>
<td>21</td>
</tr>
<tr>
<td>3-4</td>
<td>36(39)</td>
<td>42(31)</td>
<td>14(26)</td>
<td>33</td>
<td>29</td>
</tr>
<tr>
<td>5-8</td>
<td>17(18)</td>
<td>18(13)</td>
<td>9(17)</td>
<td>15</td>
<td>8</td>
</tr>
<tr>
<td>No. of Medical Conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>26(28)</td>
<td>45(31)</td>
<td>1(2)</td>
<td>25</td>
<td>31*</td>
</tr>
<tr>
<td>2</td>
<td>27(29)</td>
<td>45(31)</td>
<td>10(19)</td>
<td>28</td>
<td>33</td>
</tr>
<tr>
<td>3</td>
<td>27(29)</td>
<td>25(17)</td>
<td>17(32)</td>
<td>24</td>
<td>21</td>
</tr>
<tr>
<td>4-8</td>
<td>13(14)</td>
<td>29(20)</td>
<td>25(47)</td>
<td>23</td>
<td>14</td>
</tr>
<tr>
<td>GP Attendances in past 12 months*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>33(35)</td>
<td>47(35)</td>
<td>9(17)</td>
<td>32</td>
<td>60*</td>
</tr>
<tr>
<td>6-10</td>
<td>34(36)</td>
<td>56(41)</td>
<td>12(23)</td>
<td>36</td>
<td>15</td>
</tr>
<tr>
<td>11-15</td>
<td>22(23)</td>
<td>28(21)</td>
<td>25(47)</td>
<td>26</td>
<td>20</td>
</tr>
<tr>
<td>15 plus</td>
<td>5(5)</td>
<td>4(7)</td>
<td>13(19)</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Hospital Admission past 12 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>68(70)</td>
<td>118(82)</td>
<td>34(65)</td>
<td>25</td>
<td>21</td>
</tr>
<tr>
<td>Yes</td>
<td>29(30)</td>
<td>26(18)</td>
<td>18(35)</td>
<td>75</td>
<td>79</td>
</tr>
</tbody>
</table>

* where GP attenders as a group differed from self-help group members in a significant manner, p<0.05 using Pearson's Chi square. Within the GP attenders, there were also significant differences across regions at all levels using Chi-square except with number of repeat prescriptions and number of hospital admissions.

Table 7.2 Profiles of 294 consecutive general practice attenders on long-term medication located in NSW, ACT and Melbourne and self-reported socio-demographic, health care and health status profiles of 42 self-help group members.
Figure 7.1: SF-36 Scores among general practice attenders
<table>
<thead>
<tr>
<th>SF-36 scales</th>
<th>Age / Gender</th>
<th>GP attenders (Total n=294)</th>
<th>Self-Help group members (Total n=42)</th>
<th>Differences GP vs Self-Help groups Mann-Whitney-U test p values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health</td>
<td>Males ≥65</td>
<td>68 (58)</td>
<td>70 (13)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>72 (57)</td>
<td>78 (3)</td>
<td>0.8</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>67 (98)</td>
<td>72 (24)</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>69 (82)</td>
<td>62 (2)</td>
<td>0.9</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>Males ≥65</td>
<td>68</td>
<td>51</td>
<td>0.02*</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>73</td>
<td>70</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>49</td>
<td>64</td>
<td>0.06</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>64</td>
<td>62</td>
<td>0.96</td>
</tr>
<tr>
<td>Pain</td>
<td>Males ≥65</td>
<td>40</td>
<td>65</td>
<td>0.003**</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>49</td>
<td>50</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>58</td>
<td>75</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>47</td>
<td>54</td>
<td>0.93</td>
</tr>
<tr>
<td>Physical function</td>
<td>Males ≥65</td>
<td>55</td>
<td>57</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>53</td>
<td>56</td>
<td>0.3</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>60</td>
<td>70</td>
<td>0.23</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>49</td>
<td>50</td>
<td>0.8</td>
</tr>
<tr>
<td>Social limitation due to health</td>
<td>Males ≥65</td>
<td>65</td>
<td>78</td>
<td>0.01**</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>75</td>
<td>59</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>75</td>
<td>80</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>67</td>
<td>62</td>
<td>0.9</td>
</tr>
<tr>
<td>Role function</td>
<td>Males ≥65</td>
<td>73</td>
<td>75</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>73</td>
<td>83</td>
<td>0.04*</td>
</tr>
<tr>
<td></td>
<td>Females ≥65</td>
<td>77</td>
<td>80</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>72</td>
<td>66</td>
<td>0.8</td>
</tr>
</tbody>
</table>

*Higher scores mean better health

Table 7.3: Mean SF-36 scores reported by male and female patients of different ages among the 294 general practice attenders and 42 self-help group members. P values related to Chi-Sq values of differences in SF-36 scores in 293 general practice attenders on repeat prescriptions compared with 42 self-help group members.

The mean general practice attender scores and self-help group scores were remarkably similar with one or two exceptions, when compared by age and gender. Adult males in self-help groups had worse self-rated health, but better pain scores and less social limitation because of illness (they attend self-help groups?) than general practice attenders. However, numbers are very small in the older age group. Although not reported in the tables, the self-help group members had significantly lower mean scores than the general practice attenders on IIS scores as rated by the participants (discussed in
Chapter 9) and life-threatening and disabling scores as rated (blind) by the author. Differences were identified using Pearson's chi-square test of significance.

<table>
<thead>
<tr>
<th>SF-36 scales</th>
<th>Age / Gender</th>
<th>GP attenders on repeat prescriptions (GP) (Total n=294)</th>
<th>ACT community (ACT) (Total n=555)</th>
<th>Differences GP vs ACT Mann-Whitney U test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean scores*</td>
<td>Mean scores*</td>
<td>p values</td>
</tr>
<tr>
<td>Mental health</td>
<td>Male</td>
<td>&lt;50 69</td>
<td>80</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 69</td>
<td>78</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 72</td>
<td>87</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 70</td>
<td>75</td>
<td>0.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 66</td>
<td>74</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 64</td>
<td>78</td>
<td>0.05</td>
</tr>
<tr>
<td>Pain</td>
<td>Male</td>
<td>&lt;50 54</td>
<td>76</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 48</td>
<td>78</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 48</td>
<td>75</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 61</td>
<td>82</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 60</td>
<td>69</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 45</td>
<td>71</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>Male</td>
<td>&lt;50 57</td>
<td>85</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 69</td>
<td>72</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 66</td>
<td>74</td>
<td>0.1</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 65</td>
<td>75</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 67</td>
<td>68</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 62</td>
<td>70</td>
<td>0.05</td>
</tr>
<tr>
<td>Physical function</td>
<td>Male</td>
<td>&lt;50 61</td>
<td>93</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 57</td>
<td>83</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 50</td>
<td>77</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 66</td>
<td>88</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 58</td>
<td>78</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 48</td>
<td>74</td>
<td>0.05</td>
</tr>
<tr>
<td>Social limitation due to health</td>
<td>Male</td>
<td>&lt;50 74</td>
<td>90</td>
<td>&lt;0.02</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 66</td>
<td>86</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 67</td>
<td>90</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 79</td>
<td>83</td>
<td>&lt;0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 75</td>
<td>100</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 66</td>
<td>82</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Role function</td>
<td>Male</td>
<td>&lt;50 58</td>
<td>93</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 70</td>
<td>88</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 76</td>
<td>93</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>&lt;50 65</td>
<td>87</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-64 61</td>
<td>85</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt;65 68</td>
<td>79</td>
<td>0.1</td>
</tr>
</tbody>
</table>

*Higher scores mean better health

Table 7.4: SF-36 scores in 294 general practice attenders on repeat prescriptions compared with 555 members of ACT population sample. Mean scores (and p values Mann-Whitney U test for general practice attenders vs others)
Table 7.4 reports general practice attenders’ scores compared by age and gender with the ACT community sample. Most differences were significant with lower scores for general practice attenders indicating worse outcomes. The general practice attenders appeared to be particularly disabled and in pain in contrast to the community sample with worse pain, social limitation due to illness, physical function and role function. Self-rated health was worse in the general practice attenders, but the difference did not reach statistical significance in all age groups. While males in general practice had worse mental health than self help group members, they had similar levels of mental health to women in general practice.

Discussion

Do long-term repeat prescriptions identify generic chronic disease and illness in general practice?

General practice attenders on repeat prescriptions were heterogeneous with a wide spread of ages, social class, occupational groups and living arrangements; which varied, according to the practice setting in rural New South Wales, ACT and Melbourne or whether selected through self-help groups in the ACT.

The most common conditions in those selected through general practice surgeries were hypertension, osteoarthritis, ischaemic heart disease, asthma, and diabetes. Despite the non-random sampling of the study general practitioners, these disease profiles were remarkably similar in content and rank order to the chronic disease profiles documented by the national AMTS sample of general practitioners. The AMTS with its national general practice sampling frame is used as a gold standard for comparison with the study sample. Because the AMTS only achieved a 54 per cent response rate, it may be subject to similar biases as this purposive general practice sample. However, both studies systematically sampled consecutive attenders.

The similar rank order but greater percentages reporting diseases in the attenders were noted. These differences could be explained by the fact that those surveyed listed all their diagnoses assisted by research assistants, while the AMTS documented only those managed in the consultations under study. Also selection by being on repeat prescriptions have skewed the sample towards conditions that require or are likely to receive long-term pharmacological intervention. It is of interest to note that the levels of mental health were similar in males and females in the self-report survey, yet in Chapter 5, women were much more likely to have a psychosocial diagnosis in chronic physical encounters. Is this due to male stoicism and unwillingness to disclose problems or GP difficulty at detection?
Both surveys identified over 100 ICPC conditions recorded at least once, highlighting an often unrecognised vast range of conditions managed at least partially in general practice. This supports the need for non-categorical markers of chronic disease. Without such an approach, only the common or conflictual conditions achieve a high profile in general practice or other research and quality studies. It also appears, because of the similar profiles from the AMTS general practitioners and reported by the general practice attenders in the study, that repeat prescriptions identify generic chronic disease as managed in general practice.

Patterns of self-rated health, pain, physical function, role function, social function and mental health in general practice attenders on repeat prescriptions varied by age and location, but overall indicated considerable morbidity or illness burden. Self-rated health is recognised as an independent predictor of mortality, above traditional risk factors and medical diagnoses (McCallum, Shadbolt and Wang 1994). Approximately 50 per cent of general practice attenders on repeat prescriptions in the three locations had poor self-rated health. Self-rated health was particularly poor in those over 50 years. All indices were worse in the general practice attenders and self-help group members compared with the ACT population sample. Overall, the self-help groups had better or slightly better profiles than the general practice attenders, but scores were remarkably similar. The self-help group participants, very highly self-selected, were also generally younger and more educated than the attender sample. Based on these comparisons, general practice attenders are shown to be a high-need group with considerable morbidity, worse than people in the general ACT population and similar and worse than groups in the community who are formally identified with chronic illness.

In summary, repeat prescriptions identified a group with chronic disease and considerable morbidity. The group of general practice attenders identified, had similar morbidity profiles compared with chronic disease self-help group members, but significantly greater morbidity burden than an ACT community sample. However, the relationships between individual SF-36 scores, chronic illness and the impact of chronic illness require further understanding. The next section explores the perceptions of chronic illness of people on repeat prescriptions in the interview study.

However, SF-36 scores do not describe people’s experiences of illness: the personal construction of living with poor health. Thus, the experiences of illness and disease of general practice attenders on repeat prescriptions were explored using open-ended interviews.
Chapter 8

‘ Naming and framing illness and disease’:
experiences of people on long-term repeat prescriptions

Abstract

Chronic illness was constructed as a broad range of experiences, ranging from a minor irritation in ten per cent, to being seriously disruptive in 20 per cent, of study participants. Many forces however, acted to prevent disclosure of chronic illness ranging from internal emotional coping strategies, such as denial, to external social pressures or labelling that stigmatised and promoted stoicism. People generally resisted being labelled as chronically ill or having chronic disease, when they felt well or were coping well enough. When the burden of morbidity became difficult in physical, social and or psychological domains, they felt forced to acknowledge ‘chronic illness’. Illness then was borne according to their life stage, personal resources and life expectations. The threat of death and living with loss were important themes. Coping with pain, breathlessness and debility were often major challenges, as was the loss of self and one’s identity. The majority of GP attenders on multiple medication for complex chronic conditions experienced illness to a significant degree. A minority expressed suicidal ideas.

Experiences of disease, illness and treatment

Interviews with a subset of consecutive GP attenders on repeat prescriptions

In this chapter, I explore the ‘experiences’ of patients on long-term medication for medical problems. In chapters 2 and 3, I reviewed literature about the experience of chronic illness and the categorisation of disease, health and illness and sickness. A feature of this review was the different systems of categorisation. Illness is seen as a highly personal experience. Illness and its care are is non-specific items within biomedical systems and actions. Quality of life and functional capacity measurement are externally derived descriptions, while society overtly or covertly assigns a ‘sick role’. These categorisations including the sick role, if assigned by society to control the deviance of illness without due deference to the need to alleviate the suffering of the chronically ill are potentially problematic. The ignoring of illness, by not classifying it, is equally so. Analysis of consultation profiles in chapters 5 and 6 indicated that GP attenders were managed in a chronic disease rather than a chronic illness
Another explanation might be that such GP attenders might not experience similar illness to that described in the chronic illness literature. Yet, health status profiles of such GP attenders reported in chapter 7 were poor. Therefore, I explored the nature of chronic illness in general practice attenders. What is reported here is part of a larger study including audio-taped sequential consultations.

Methodology and participants

Of the general practitioners recruited for the quantitative study described in chapter 7, a subset were also invited to participate in the patient interview study. Within cost constraints, the GPs were chosen to represent the broad diversity of practices: single-handed and group practices, both small and larger, and community health centres within three locations: rural, urban, and inner-city. Forty-eight patients (80 per cent of those approached) agreed to be in the interview study. Twenty three general practitioners consented to be interviewed (see Chapter 11). Participants are listed in Figure 8.1.

GPs and their attenders on repeat prescriptions sample

46 GPs
Originally approached

23 GPs
50%
Participated in study and were interviewed

14 GPs
Invited GP subset provided consecutive patients for interview / consultation study
7 female & 7 male

48 GP attenders
Repeat prescriptions (>12 months)
No primary psychiatric history
Complex chronic conditions

Figure 8.1 General practice participants in the interview as reported in Chapters 8, 10 & 11.

1 I was also principal investigator for the qualitative aspect of the study funded by the General Practice Evaluation Program as part of the integrated study. The co-investigators were Dr Jeanne Daly, Senior Lecturer, La Trobe University and Professor R M Douglas, National Centre for Epidemiology and Population Health. Three research assistants worked as interviewers on this project: Gail Roberts, Naila Rahman and Susannah Churchill. Their backgrounds were in community nursing and social science.
On prearranged weekdays, research assistants visited each general practice at the start of a normal surgery. Research assistants recruited up to 5 consecutive attenders of people with “complex chronic conditions”. The recruitment threshold was set at a higher level of disease complexity than being on repeat prescriptions. The general practitioners selected from their appointment list, those patients who in their opinion had significant chronic medical disease, but not primary psychiatric problems. Significant chronic disease was defined as: 2 or more repeat prescriptions for more than one chronic condition (co-morbidity), or for a chronic disease that was multisystem or had complications. The patients were not to be in a terminal phase, were to be under the care of at least 2 specialists with a good command of English (See Appendix 2.2).

Box 8.1. GPs and their attenders - Participants in the study of ‘Experiences of disease, illness and treatment’ analysed in Chapters 8, 10 and 12

- Thirteen inner city Melbourne attenders of three general practitioners; one from a large group private practice, one in a single-handed private practice, one from a larger community health centre. Two of the general practitioners were male, one female. All were full-time and Australian trained.

- Fifteen urban Canberra attenders of eight general practitioners; one in single-handed private practice, three single-handed private practice but with permanent assistants and four were from four different sized community health centres, which were closed after the study period; two of the general practitioners were male and four were female. All except one was full-time, three were overseas trained. The rest were Australian trained.

- Ten rural NSW attenders of four general practitioners in two, two-general practitioner practices. All general practitioners were male, in full-time practice and Australian trained.

Fourteen general practitioners (7 female, 7 male) were purposively selected to represent urban, rural and inner-city group and single-handed general practice. They were identified through GP networks as being medical teachers and ‘good’ GPs. Specifically, three GPs were located in inner-city Melbourne - 1 from a large group practice, 1 from a single-handed practice and 1 from a large community health centre. Nine GPs practiced in Canberra, 1 in a single-handed practice, 2 were in single-handed practices but with assistants and 4 were from community health centres which were closed after the study period. Four GPs were from rural two-GP practices. The interviewers approached the first five named individuals when they attended the surgery, explained the study and requested to make a time for an interview at their convenience at the place of their choosing, usually the home. (See Appendix 2.4)

Sixty-seven percent (28) of the patients who took part in interviews were female and 33% (14) were male. They ranged in age from 21 to 81 years of age. The mean age was 65 years and the median was 69 years. Twenty-nine % were under the age of 60, 22% were in their 60s, 47% in their 70s, and 1 patient (2.4%) was in their 80s. Three patients (7%) were single, 50% were married, and 43% were widowed, separated or
divorced. Thirty-three percent were living alone, 45% were living with their spouse and 21% were living with a family member. Sixty-nine percent were on benefits, or superannuation, 10% were employed full or part-time and 14% were looking after a home and family. Ten patients were from rural NSW and ACT, 13 were from the inner city Melbourne and fifteen from urban ACT.

Interview proformas contained a series of open-ended questions around key themes that were identified by working through analyses of discussions with key informants: colleagues and patients; analysing themes from audio-taped focus groups, and revisiting the literature (see Appendix 2.4). At least one formal long interview was conducted with each participant in their home. The study data-set is described in Box 8.2.

Box 8.2. The data-set of the study of 'Experiences of disease, illness and treatment'

Forty-eight patients of four rural general practitioners, eight ACT general practitioners and three inner city Melbourne general practitioners who had complex physical disease, without primary psychiatric disorder, with good English were recruited. The study data included:

- 1 long interview with patients conducted over one to three interview sessions using a semistructured interview schedule and a questionnaire proforma (conducted by research assistants)
- unstructured interviews of all participating general practitioners (conducted by the author) and
- field notes written by interviewers related to their contacts with patients and GPs

Analysis

Analysis of the transcribed interviews was conducted using grounded theory principles (Charmaz 1990). Transcribed interviews were read and coded by the interviewers who also wrote field notes about their visit(s) and informal contact(s).

The components of the analysis of the interviews were:

(i) coding of the GP attender interviews and the GP interviews
(ii) the entry of these codes into files numbered by Ethnograph
(iii) initial analysis of this data to produce a description of: the GP attenders experience of illness (chapter 8) and needs, wants and satisfaction in relation to GP care (chapter 10) and GP experiences of chronic disease and illness care (chapter 11)
(iv) analysis of the coded consultations through writing and discussion within the research team

Ethnograph V3.0 was used to assist in the management of the data during the process of analysis. Analysis of consultations consisted of attaching codes to sections of text that could then be retrieved. The codes used were not mutually exclusive and were generally of the type described by Seidel, Friese and Leonard (1995) as a heuristic device for further examination and comparison.
The interviews of the patients were coded by the author, the social scientist in the study, Dr Jeanne Daly and the interviewers. Written notes and marked transcripts were used. In order to improve validity, meetings were held to discuss the similarities and dissimilarities in the coding and interpretations by the researchers. Preliminary writing up of the research was done collectively by all members of the team. What is presented here is the author’s personal secondary distillation of the key themes developed from the primary analysis with Jeanne Daly and Gail Roberts (interviewer), building on the fieldnotes and preliminary investigation of Susannah Churchill, Nalia Rahman and Gail Roberts (interviewers). The general practitioner interviews were conducted, analysed and coded by the author alone, supported by a process of dialogue with Jeanne Daly.

In reporting the findings and analysis, participants are referred to by first name pseudonyms. In the patient interviews, the GPs are given the title of Dr and an initial which is also a pseudonym to avoid confusion.

Limitations of the approach taken

This component of the study was the first stage of the qualitative study. It aimed to establish frameworks, categorisations and operations around generic chronic illness in general practice using grounded theory principles. The intention was that this would break the ground for more definitive research to be conducted at a later date. This qualitative study, therefore, had several limitations. Firstly, in order to cover the breadth of general practice, it was set in three locations. The result was that three different interviewers conducted the long patient interviews with different levels of skill and training in the three settings. To counteract this problem, a detailed proforma with a list of interview questions and prompts were provided, together with training sessions (see Appendix 2.5). Respondents were also asked to complete a structured questionnaire assisted by the interviewers (see Appendix 2). Another limitation was that this was a highly selected sample of GPs, of recognised ‘good quality’ and may have self-selected patients with more severe illness attracted to their practices. The other limitation due to the difficulty of recruiting and interviewing people who are ill and the time it took to visit them at their houses, when sometimes they were not available for pre-arranged appointments because of hospitalisations or other reasons. As a research team, we didn’t really want to be an excessive trouble to them and our resources were limited. The result was that analysis (of patient interviews) was conducted post hoc and not taken back to each individual for validation. However, analyses have been presented to self-help group members and other general practice groups for external validation of the conceptualisation. Also, I was funded to conduct a study into collaborative relationships between general practitioners and self-help groups, where the same issues were raised and discussed in focus group settings that provided cross validation (McGuiness 1996).
Results

Patient interviews

Having chronic illness

When people get ill, argues Charmaz (1991:13), they see the illness as a temporary interruption in their lives, leading eventually to recovery. Chronic illness can loosely be described as illness from which there is unlikely to be recovery. GP attenders did not, however, have an a priori concept of chronic illness nor a chronic illness ‘literacy’. Illness was an external construct of the researchers. Thus, in the course of the interviews chronic illness as a concept was negotiated between researchers and interviewers and indirectly with participants. The concept included pain, debility, physical, psychological and social distress and ‘just feeling plain crook’ or other symptoms or health problems that interfered with people’s quality of life over long periods of time.

Five of the participants (in relation to study constructs of illness) stated that they did not consider themselves ‘ill’ or ‘chronically ill’ that is they were generally asymptomatic. They declared, only a minor impact of their condition. Sarah, who for example, is quite determined to have her medical condition affect her life style as little as possible, and admitted to finding it ‘irritating’ to have to take medication, states that:

Sarah: I never really thought of it [chronic condition characterised by breathlessness] as an illness, I just thought of it as being inconvenient in some ways... I don’t really think of it, that I have a disease at all.

The remaining 43 patients saw themselves as ill to some degree and reported the incurable nature of their symptoms.

Rose: Yes, I feel pain but there is nothing they could do about that.

Having chronic illness or disease was viewed by a significant proportion of the group as being undesirable because it implied a failure of the body or mind that was incurable. None of the study participants chose to have chronic problems; neither the diagnosis of disease, nor the suffering due to symptoms.

However, five of the patients on long-term repeat prescriptions (~10%) found the notion of being ‘ill’ or ‘chronically ill’ very difficult.
Paul: There isn’t anything that can actually be done about it (the condition). No one can relieve you of those things. I think essentially you know even if I had people constantly around me, [it] may make it tougher in some respects. Yeah I think I could probably look at that (death) if I find I am just at the end of it all. Yeah I am just trying to prepare myself for all the eventualities that just may occur.

Death and suffering confronted Paul, this youngish man aged 32 years, as he faced his future with a failing body. His condition isolated him from his peers, but that was not entirely bad. Contact with peers confronted Paul with what he was missing in a typical life stage. His real dilemma was how to live in the present while preparing himself for the uncertainties of, yet inevitable, pain, suffering and ultimately death. Paul is in touch with his conditions and his prognosis and confronts its stark nature.

The remaining 60 per cent struggled to maintain equilibrium in chronic illness.

Brenda, in her late forties experiences different types of chronic pain, including chest pain, diverticular pain and muscular pain. She did not want to focus on this pain - she tried to ignore it and just get on with her everyday activities. She claims that her pain ‘is not permanent’ and that ‘giving in’ is ‘self-indulgent’.

These statements are echoed by John.

John: I am not too bad, I am not dying or anything, you know. You get a bit crook but a lot of people make out worse, say they are worse than what they are, don’t they? And as I say, I suppose I am a bit tough probably, I am used to pain and don’t worry about it.

Both Brenda and John (and a third of those interviewed) are ‘tough’ in the face of symptoms and the threat of death and deny the ‘self-indulgence’ of illness. Is this a reflection of broader community attitudes to those who are ill?

It is possible that an apparent non-disclosure of illness and suffering in the previous two interviewees was because they did not experience illness. Yet by their own admission and description they experienced considerable suffering. Lack of trust in the interviewers or courtesy bias towards their GP may have impeded their self-exposure. It is possible that the participant’s continued reliance on the general practitioner heightens their sense of vulnerability (including where participants were not convinced that the information they disclosed to a confidante such as the interviewer, would remain confidential).
Enid: Most people, as you probably know, they're probably not
game to say anything, you see, we're in the doctor's hands, and we're
terribly frightened. I've heard some terrible things that go on, you know,
and it's unbelievable, whether they are true or not, I don't know. But I
can understand that they have, because your life is in their hands, there's
no doubt about that.

However, this was an unlikely explanation for the majority, as only one participant
expressed any such reluctance. It was very easy to get the majority of participants to talk
about their other negative experiences such as with specialists, previous GPs and the
health system. Another explanation for non-disclosure is the study design and execution.
The preliminary nature of the study with insufficient time to build up trust, the skill of
the interviewers may have contributed. However, this phenomenon was detected by all
the interviewers and remarked upon particularly by the most experienced interviewer.

The 'non-ill' or 'reluctantly ill' cases (a third of participants) were explored in more
detail. As already stated four thought of themselves as being well (having medical
conditions but no illness or sickness) and did not appropriate the sick role (Parsons
1951). The second and larger group - the reluctantly ill - believed that the role of the
patient is to get on with life and if you don't cope it is your own fault.

Zelda: You have sort of learnt to cope with things and just get on
with your life. Well I think life teaches you and if you don't learn it is
your own fault.

For the others, it appeared that they had significant symptoms, but their coping
mechanisms were very fragile and emotion based, supported by mechanisms of denial
(Felton 1984; Folkman et al. 1987; Toseland, Blanchard and McCallion 1993). This was
not challenged by the interviewers.

Brenda, for example, complained that she was being undermined by having to focus on
the illness she was feeling which she chooses not to focus on, claiming that if she did,
she would 'collapse in a corner'. She implied that it was self indulgent to focus on such
things. Importantly, Brenda has other members of her family living at home who are
experiencing the effects of ill health - she often 'puts herself third' as she has to care for
them.

The 'toughness' thus appears to be related to maintaining an acceptable internal
coherence and social position. Such barriers to disclosure may be related to wishing to
present a socially acceptable 'coping' self to oneself as well as to the external world
(Robinson 1990), and stoicism (Waitzkin, Britt and Williams 1994). Participants did not view the sick role as a protection, nor suffering as ennobling. They appeared to perceive chronicity in the sick (or even an impaired) role to be highly socially undesirable.

Puzzling symptoms (illness) that do not fit into a clear disease framework are ignored.

Jean: Um...this disease, probably that's been there for a long time and they didn't know it. Matter of fact, I knew before, but I didn't know what it was. And um... then I had kept going back to this GP I don't know! Sometimes I was told that... I thought, or they thought... that I just want attention.

Jean: Eventually the doctor finds out about it, and she said the problem is there. (It) is a condition must be there the last thirty years, you know, and I was, I didn't know why I was and I was depressed ..., and... it comes out that it was this scleroderma.

People with chronic illness are often blamed or stigmatised for their condition (Scrambler, 1982). Ken struggles with confronting and accepting the fact that he has a serious problem. He is afraid of what an accurate diagnosis might do for his insurance and employment status. He tries to bypass an official diagnosis. Yet, by attending a physician who did not identify the seriousness of his problem, the depth or degree of his problem was inadequately diagnosed.

Ken: He (the GP) saw the Bells palsy condition on me and asked me what had happened and tested me and tested all my reflexes, and noted that I was down on the right side, and wanted me to go to a specialist in Wollongong, and I was afraid to do that because I would lose any kind of insurance that I already had to battle for, workers compensation, I had to bring the union in to get any action. So I was in a fearful situation, because I had only just started on a new job, and was there only a month when this happened to me and I could see the rest of my life melting away from me. I asked if he would be satisfied if I went back to the original GP and consulted him and bludgeoned him into sending me into Sydney to see a specialist, Dr. X.... in Macquarie street. He(Dr X) said I was young and fit and most likely to recover for this and made a subsequent report to the insurance company that he felt I wouldn't have any post epilepsy problem and that was it and he discharged me from his care.
This quote describes ambivalence about the value of labelling or diagnosing the sick role. Firstly, Ken is trying to avoid labelling that will have a major impact on his economic situation and career. However, by doing so he is denying himself the opportunity for adequate assessment and treatment. Diagnostic labelling or even worse, the labelling of an inappropriate sick role by general practitioners or social rejection of those with an appropriate sick role can close off people’s narratives of their illness that promotes healing (Kleinman and Kleinman 1991). However, responsible diagnosis or labelling can provide the avenue to help and a social role appropriate to the level of disability or impairment.

Uncontrollable chronic disease may thus be seen as a process that sets up mutual accusation and blame for the patient who is not ‘getting better’: does not accept the sick role responsibilities and for society who carries the burden of the chronically ill. The medical practitioners who are failing to cure are the agents of society (Parsons 1951): This quote is an example of a GP blaming the patient for not getting better but enjoying the attention and getting secondary gain from living out a sick role.

*Dr B.* She (Alison) was very sort of dependent on the medical scene for support. She lived her illness.

Both actions serve to damage the relationship between general practitioner and patient by channelling communication down predictable (and often disease-centred) paths which may serve to cut off or stifle the patient’s expression of experiences of illness and psychosocial information gathering, and supportive illness care by the practitioner.

One participant, who was judged to be very breathless by the interviewer and apparently quite physically affected by his disease - emphysema - Reg, was emphatic regarding his perception of his health status. ‘*Oh, no, no,....only when I get depressed*’, he stated when asked if he considered himself to be ‘ill’. He seemed to equate ‘illness’ with vulnerability, which may indicate that he only feels vulnerable when he is depressed about his medical conditions and the way in which he becomes incapacitated by them (breathlessness).

Society, also, accuses those who have failed to prevent ‘preventable’ chronic conditions. Is this an unintended consequence of health promotion literature? Society in general and people who are ill in particular appear to have engendered a culture of blaming those who have succumbed to illness because they ‘have been bad’ that is not adhered to medical or health promotion advice.
Annette: But know I can see, had I have taken more care earlier, it maybe wouldn’t be as bad as it is.

As one participant eloquently described the problem of guilt at being ‘damaged goods’,

Heather: I guess they (patients who are labelled as “chronically ill”) have got connotations of always being at the doctor and being a pain in the arse.

Whilst the interviewers identified social pressures on the participants not to disclose the extent of their illness or suffering, it was not judged a problem for the analysis of the data. The participants met the criteria set out to describe what ‘chronically ill’ meant for the purpose of the study and in indirect if not direct ways did disclose much pain and suffering. However, this matter has significant implications for the general practitioner. The social discourse of illness, sickness, disease and conditions has important implications. General practitioners must be aware of the power of language and its possible implication in the communication they use with their patients.

Communication and ‘categorising’ or ‘labelling’ by general practitioners (diagnosis) and others (social perceptions of sickness) may have several effects on individuals, not least of which is stigmatisation (Blaxter 1978; Scrambler 1982; Yardley et al. 1992) and ‘pigeon holing’ (Robinson 1990; Nijhof 1995). There is also some literature which suggests that patients have a worse health outcome when they receive an inappropriate diagnosis and embark upon an inappropriate sick role (Daly 1989). Sometimes the risk of infection is an issue but stigma can also attach to people who are seen as imperfect or deficient, causing embarrassment because they cannot fulfil cultural norms of social interaction (Scrambler, 1984: 208-9). Since this threatens the sense of self, people with chronic illness may be secretive about the illness, hiding the stigmatising condition, especially from public audiences. Medical practitioners consulted about the illness, like the interviewers, may be placed in an ambiguous situation somewhere between a private audience with whom intimate details are shared and a public audience from whom personal details are withheld. Yet, the ambience of suffering and the impact of illness may be detected in individuals, as was done by the interviewers, without forcing a painful and perhaps damaging self-exposure from those who rely on denial for self-protection. The art of medicine is to ascertain when such labelling gives permission for patients to adopt an appropriate sick role that facilitates better coping and to withhold labels when it promotes a worse outcomes and an inappropriate sick role.

The pain of having chronic disease and illness may be more poignant in today’s ‘risk society’ with its youth orientation, health promotion and ethos of self-care, and the
pluralistic loss of family and community structure (Turner and Samson 1996; Lupton 1997). Ken, a young man, with a serious condition that was reducing his intellectual and physical capacities, yet he remained highly articulate and insightful.

Ken: I was so psychologically destabilised by the grief of losing who I was and then coming to grips with the degenerating condition.

Ken was terrified of disclosure to employers and insurance companies. His coping was hampered by a perceived rejection by society and alienation from his peers. His 'impaired role' did not help him cope, particularly in the knowledge that his course was all downhill and he preferred to protect himself from exposure to 'normality'.

The impact of illness

While around a third of study participants denied or were guarded in the disclosure of significant illness for the range of reasons already explored, the remainder of patients acknowledged chronic illness with significant impact on biopsychosocial domains of life. One person died during the 18 month study period, one marriage broke up and ten hospitalisations occurred. None reported a 'good' chronic illness experience.

The most positive illness experiences were in those who saw their health problems as an inevitable accompaniment to ageing, who had stable personal lives with satisfying personal relationships and able to function and still enjoy their life. As one elderly person said:

Beryl: I've had a good innings.

Josie in her mid forties, provides a stark contrast, with those who accept their disease and manage within the context of their lives. She describes many worries and severe hardship, both physical and emotional, over the years that she believes (and it appeared to be the case) that have aged her considerably. “She is about five feet four inches, is over weight and her skin is quite dry and lined. Her hair is lank. Josie has a nervousness about her; she fidgets a lot and moves around almost constantly as she talks with you” (field notes). After agreeing to participate in the study, Josie started telling the interviewer how she was going to see the doctor to get 'the nicotine patches' to try and give up smoking. She claims she had 'tried everything' and seemed fairly unhopeful about her chances of giving up. Indeed, she said that her illness [emphysema] had killed her mother and her sister 18 months after they were diagnosed. She expected a similar fate and that it would be 18 months since her diagnosis a little later in the year. Josie had many problems including cancer. The diagnosis of a chronic illness such as cancer and
the treatment, including surgery, may completely disrupt families which are already vulnerable with the result that the ill person is left bereft:

Josie: I got [the operation] done on the 1st of August and me husband chucked me out on the 23rd of August, ... My husband wouldn’t let me see the kids. That nearly destroyed me. So I had to go and see a shrink. ... I thought well I wouldn’t fight him, you know. So I didn’t. I ended up with naught anyway.

Josie’s breathing has become steadily worse over the last two years or so, and she appears to have lost the battle to keep her family together and her son out of trouble with the police.

Jean is an older woman with an apparently less severe physical disease state. She chooses to stay in her house most of the time as she claims she feels ‘no better’ regardless of whether she goes out or stays at home alone. Apparently she feels too unwell to do so. She was unhappy that she was putting on weight. Jean now feels even less inclined to go out because she feels so fat. Her experience is that of loss.

Jean: ...as the disease generates, you know you’re losing more of the use [of your joints].

Dealing with uncertainties and the threat of death was another major trauma. Deborah’s battles with breast cancer were far more prolonged than anyone anticipated.

Deborah: I was told (by doctors)... that ah... it was going to be quick and going to be nasty and the remissions were not for me, and I think that was totally wrong, but it put myself and my family through a lot of trauma um...

Yet without hope people could die or have their death hastened by these uncertainties. The emotional pain of hopelessness could be as deadly or more deadly than the physical disease. Majorie, who also had breast cancer, witnessed this in a friend.
Majorie: I had a friend, a neighbour, a friend down the back with breast cancer, and this was just last year and they told her that she'd be dead in three months, and she just gave up I mean she was still capable of walking around the house, going outside and she just refused to do anything, took to her bed, until she died, and she did die in three months, but she just refused to eat as well, so really what she died from was lack of nutrition.

Death lurks behind the diagnosis of chronic disease. The threat of death is ever present, and, particularly when it is uncertain, it is very difficult to live with. Acceptance of the shadow of death and the relinquishment of a full life are the lot of those with chronic disease or illness in general practice. Patients do not make any distinction, nor do they dwell on the nature of the pathology. Only the impact on life, its course and its end are important. The losing of life or function or hope and/or the unwelcome visiting of pain and debility characterise the chronic illness of general practice. The suffering due to the illness was consistently discussed by participants in terms of self-blame, helplessness accompanied by a lack of support in preference to the experience of physical symptoms. The results of an analysis of consultations among study doctors and patients is described in Appendix 3. This study yields detailed descriptions of pain, symptomatology and treatment given to the GP, yet in the interviews by research assistants, people talked about the ‘meaning’ of their condition in prognostic or psychosocial terms more than the actual symptoms. The interview schedule structured this to a greater or lesser degree. However, this also reflects the role perception and culture of the general practice.

Living well with chronic disease and illness

The task which faces people with chronic illness is to deal with the bodily dysfunction and adjust to the social experience of illness. Of course the ultimate is a cure or apparent cure that relieved the symptoms.

Leo: Yeah ... the most serious thing I don’t think there's any doubt about this, ...four bypasses which I've had, fortunately. I should say the bypasses were a fantastic success as far as I know......but when I had the operation actually I was pretty ill... I didn't think I'd ever come back to Canberra.

For the others for whom there is no technological or medical ‘cure’, this task of living with illness can be met by transcending, living with and managing or just not coping. A group who were notable in the transcendence of their illness and disease were those who became active in the community or in self help groups.
Over the past few months Alice has been plagued with an exacerbation of her long term health problems. This culminated in a recent hospital admission a few weeks ago. Since her discharge from hospital, Alice claims she 'has not been the best'. Despite this, she has continued to keep up with her many social activities. She never 'gives up'. She learnt this from her mother. Her tenacity is almost humbling; she has several serious health complaints and believes her health is declining yet she nevertheless keeps on doing many things for other people, while literally catching her breath. Alice, by her own admission, is a 'born organiser' and has organised many social functions and, even the very beginnings, of some of the groups to which she belongs. She is a committee member at her local community health centre and is well known in the community.

Alice: I think it (illness) has slowed me up. But I have kept going... I don't let anything get to me.

Twenty (40%) of the participants worked very hard to 'transcend' (Bury 1982; Charmaz 1991) their illness and disease in as 'normally' as possible. They managed to function and maintain independence and control.

Doreen: I accept my illness, but I have control over my life.

Rachael, a late middle aged moderately well-off educated woman, has had syndrome X: diabetes, hypertension and hypercholesterolaemia with the resultant vascular disease for most of her adult life.

Ruth presents a case that is rather typical of the image of people with complex chronic conditions that the Coordinated Care trials are attempting to manage better. She has complex disease with multisystem involvement, multiple specialists and has had multiple investigations and operations with polypharmacy and multiple allied health service use. Her patient profile is common in general practice, except her condition started earlier than most and therefore she is younger than the typical case.

Rachael describes her condition. Hidden beneath her cheerful manner is a very strong spirit with the desire to maintain control, even to the point of saying enough is enough if she feels that she is becoming a burden and that life is not worth it:
Rachael: The drugs for hypertension which was the first problem I had were very poor and didn’t cope with the hypertension very well so it was up and down, up and down, not controlled really, for years. Umm well every illness I have had has had to have something done to fix it, now my heart is in permanent atrial-fibrillation, do you know what that is ... you know how your heart beats ti boom, ti boom, ti boom well mine goes boom, boom boom boom boom boom, boom, all over the place all the time, it is permanent and it has been like that for maybe five years and they are just going to leave it like that and so what they do then is give you a drug to make sure the beat stays below one hundred beats a minute so you don’t fall into walls and get giddy and generally can’t cope. So I am used to that and I take drugs for that. I have to take a lot of drugs. So I take drugs for my hypertension, drugs for my diabetes, drugs for thinning my blood to try and stop me having strokes and drugs for diabetes. So there is quite a lot of them.

Rachael has continued specialist interventions and treatments. Coronary by-pass grafting has failed and needed repeating. Despite intense exercise and moderation in diet, she maintains 84 kilograms in weight and has been shouted at by specialists because she is non-compliant. She maintains control but illness is threatening:

Rachael: And no I manage very well. I still go to the school and teach the reading twice a week and I go swimming twice a week because my legs are so painful now because the arteries are blocking up that I can’t walk very well so .... but I still do. I walk, you know they pain but I still walk, but not ... you know I can’t really do it very well and I am coping very well but I got a bit of a shock this morning when they told me my legs were very bad again because I would hate to have to have them off. You know and that can happen and I don’t want to get around with no legs and a wheel chair and.... I would prefer to die before that happened but of course you can’t just die when you want to but you should be able to. I would like to be able to anyway but I don’t want to ever be a burden on my children .... they would be very helpful if I wanted them to but I would prefer to manage things on my own. I live on my own.

Different participants found different ways of coping. Brian was typical of the ‘one day at a time’ group who lowered their sights and expectations of life.
Brian: Well I suppose you've got to carry around all these medicines, and rubbish and that sort of thing and if you walk too far, you have to use a bit of Ventolin, and walk too far on the legs, you end up using the walking stick, and all this sort of thing, but I get around and do things, I don't think I'm that bad really.

Brenda stated that 'I can live with everything', indicating that she has accepted her health as part of her 'self'. She doesn't make a judgement regarding what state her health is in, but rather, focuses on how she can work with her body. She preferred to focus on how she was feeling at a particular time and doing all she could with consideration for how she was feeling then (even though 'she feels quite poorly at times'), stating that it was almost like 'writing yourself off, instead of accepting yourself'- 'I have good days and bad days'. Brenda carries her medication with her at all times because her health can deteriorate suddenly.

Brenda has learned to 'live with those problems'- she says she has displayed a very matter of fact attitude to her health; accepted herself as she was and did what she could 'with what she has got'.

Brenda: Is there anything different in my life that I would have done [had I not been ill]... probably not. My illness ...it can make you more thankful.

Brenda walks a very difficult tightrope to maintain control.

Losing control

For the some study participants (20% of the total), living with a chronic medical condition or conditions can be disruptive (as found by Bury (1982) and Charmaz (1991)) conveying a sense of despair and loss of control to those that are ill, as well as to their family and friends.

Paul: ...before the injury. I had something to live for, to get up for...I enjoyed my work. It was at that stage yeah... about 1986 was when I came in, I came in then and I was pretty much a mess at that stage, because I had lost control of my environment.

Another participant echoed such concerns, stating that,
Frank: I had never seen a doctor in my life until I retired... The illness has affected me a lot...I just can’t get around, I can’t do nothing, you know.

Ava is a middle-aged moderately well-off urban woman, who has rheumatoid arthritis.

Ava: The mobility of the disease worries me. When my husband retires and we don’t have his wage. We wonder what’s going to happen. As the disease progresses, you’re losing more of the use (of your body)... I find that hard...

Alison had clearly felt increasingly isolated by her life-threatening illness and could not cope with her recurring brushes with death and a husband who had been ‘cured’ by the general practitioner and specialist. Her husband Brian was very grateful to the general practitioner for his help, but was unhappy that his family life had been disrupted by his and his wife’s chronic illness:

Brian: My wife left me. She does not want to live with me. She is not my wife any more. She also is ill. My children do not come. They like their mother more.

Interviewer: You said, your wife left you. Is this because oh your illness?

Brian: Oh. Partly mine, partly hers, she was a very sick woman too.

Both Alison and Brian interviewed independently after the separation were very unhappy and felt chronic ill health had destroyed their marriage and their chance of happiness together.

The task which faces the person with chronic illness is to deal with physical disruption of the disease and adjust to the social experience of illness. According to Bury (1982: 169-70), chronic illness is best analysed as a crisis, a form of ‘biographical disruption’. People find themselves in ‘a new social arena where common sense guidelines are no longer sufficient.’ Alison’s unstable illness, her ambiguous sick role and unfulfilled marital role were accusations of personal incompetence that made her social arena unbearable. The previous examples cited were with younger or the middle-aged, yet older people reported similar experiences. Nigel, for example, became overwhelmed by his illness:
Nigel: of course after I retired, then the was other illnesses set in such as angina, and ah, started to have something done about that it got worse and worse and um...well that did, it did it made me, when I knew that I had heart trouble, it ah made me very depressed and very ah... oh... what would you say, I ah...I felt I ... frightened but I was just couldn't carry, go through with it.. I thought that, you know...I felt that it was the beginning of the end.

Viola who was also in her seventies reported similar life disruption:

Viola: well I don't think, yes it is more or less a heart problem. Umm... and then oh... the disease and that's a big problem in the winter time ah... even in summertime it gets really worse - that's there for many many many years, ahh. in the beginning its was tolerable, I could cope with it because I was much younger and now through all the years I think its a lot of damage done there, its numb through. Sometimes I have problems with craft things, and I have to give up macrame. So um. that's a big problem and oh I'm frightened. The time it comes closer, it comes to where I can't do those things any more, so... and ah... the feet are numb, very numb and sometimes I can't take a walk, 'but I just keep going because I think, you know its there.

Giving up

Of the 48 participants, three expressed frank suicidal ideation, while it was hinted at in at least two others. Brenda tried desperately to cope, but after a recent exacerbation of her illness resulting in hospitalisation, she needed psychiatric help.

Brenda: I just don't like fronting up down the hospital. And saying 'well, I have to come in here because my doctor said so'. You feel like such an idiot.

Her life continued to be highly stressful with problems over access to her children, her children being in trouble with the police. Not surprisingly, giving-up and remaining off cigarettes presented a major problem. Additionally, she developed a significant back problem; possibly as a result of her life-sparing steroids.
Brenda: It’s like the straw that broke the camel’s back... having to cough when I couldn’t stand up any more and it was a big burning thing across my back...I thought I was going to die. ...It’s hopeless... a lot of the time...when I can’t do anything. When I’m down to about two steroids a day. When I get below that I can’t do anything. That’s when I go and end it all.

Paul experienced similar devastation with his condition

Paul: I would just crash out, and the family would need me and they would be making demands on me and that got to a point where I wasn’t functioning I would go down ........

Carole, a woman in her thirties in a wheel chair, self-medicated with cannabis and other drugs to deal with the loss and loneliness of her predicament. She particularly mourned the perceived loss of her sexual attractiveness, when previously she had made money from her body through prostitution.

Carole: I am no woman, no more.

Carole’s self-esteem was highly linked to her sexuality, that she believed had been destroyed through her accident and subsequent hepatitis illness and disability. She turned to drug use thereby putting her life at risk.

Achieving coherence in the face of the stresses of chronic illness

The representations of life and meaning of illness which the ill develop themselves, the private face, forms the core of the work of managing (Charmaz 1991). However, this is strongly influenced by the ‘public’ or social response.

The more supportive the environment and the better the living standards, including social and family ties and physical and economic resources, the easier it appears to cope, although a large social network depending on one may itself be a stressor.
Marg: So you see we lost their father (her husband) and then Greg and then his boy. So there was a lot of trauma going on. Whether that had any effect on me having that silent heart attack... You never know do you. Because I am not a worrier or a stressful person. You know I carry life pretty well by ear so I don't know. It happened after Greg had gone. So it could have .... Dr E said it is possible but even the hospital said "we can't tell who will have heart attacks, people we think are candidates don't and people ..." the five factors that applied, none of them applied to me. However so we lost Christian (son) this year but Keith is very supportive, considering he is at Sunbury. I have the children weekends you know. I have minded them both since they were babies and they are down .... and he rings you know. So I have got good support and I have got a neighbour across the road who is like a sister. I call her my security blanket.

Stability in the face of chronic ill-health reflects the individual’s ‘sense of coherence’ based upon the comprehensibility, the manageability and meaning of their internal and external environment (Antonovsky, 1993)? Instability and coping relate to intimate social bonds and the healing social narrative. In this case Ken has a family experience to both frighten him at his stage of the trajectory of chronic illness and to help him make sense of the family tragedy.

Ken: Yes this is just the beginning (of my decline) because I watched my uncle die, not my mother’s brother but my father’s brother. He died of liver cancer and the cancer came up underneath his skin and drove him crazy. He went yellow and then he went grey and then he finally could hardly breath at all and then he was in agony. Mum is allergic to morphine too! which makes it a little bit ....If, when, she is well enough, I think this is.... sounds funny but I try and spend enough time seeing her and talking to her because lots of things that can be said then that can’t be said later.

The intrusiveness of conditions correlates with the degree of stress induced (Rahe 1988; Weiland, Pleiss and Roghmann 1992).

Marg: But it wasn’t a sickness, it wasn’t an illness. It was just a painful sort of complaint and while I am aware of it, when I wake up of a morning, it is just one of those very inconvenient things.
Marg can cope with the pain because the condition is an inconvenience not likely to have negative sequelae. She is, as mentioned above, very connected socially to her family and deeply engaged with their lives and problems. She also has a very supportive relationship with her GP. Unfortunately, many of the ill group are not so fortunate with their condition, their ability to transcend or deny the condition and their social network.

Perceptions of illness and morbidity burden in general practice attenders - discussion

In this study, illness was constructed very much as socially stigmatising, as was being assigned to the role of being ‘chronic’. Study participants went to great lengths to avoid such labels. Admitting to illness, or accepting the sick role was associated with ‘failing’: the failure of the body, or the failure of coping as an individual. In an era of a ‘market driven’, youth-orientated and self-management of risk society (Turner 1996), chronic illness was reported to be a highly uncomfortable social state in addition to physical and psychological discomfort. People, at least the ‘silent majority’, with common chronic disease appear to have assumed a role of stoicism, perhaps men and the elderly in particular (Waitzkin, Britt and Williams 1994). This study identifies a high burden of morbidity in the general practice group with around 60 per cent struggling to maintain equilibrium and 10 per cent with some suicidal ideation.

Chronic illness as a concept remains elusive to both ‘objective’ measurement and external categorisation by interviewers (Denzin 1989). As an inner perception and experience like an unseen hand, it casts a shadow upon the social being. The social role enforced by chronic illness is the visible manifestation of such a hand.

This sick role, the chronically sick role or even the chronically impaired role, was, however rejected by patients in at least a third of cases where it was clear that they were suffering physical and or psychosocial distress over long periods of time. Have they learned ‘toughness’ and stoicism, rather than ‘learned helplessness’ from society and in particular from their GPs and other health professionals (Broomhall and Winefield 1990). However, Parson’s (1951) sick role did not originally imply ‘learned helplessness’, perhaps it has acquired that meaning over time and the additional meaning of ‘damaged goods’ and victim blaming. While ‘learned helplessness’ is an unhelpful strategy, the toughness and stoicism engendered by the lack of an ill role also prevents constructive and positive negotiation through chronic illness between patient and society (doctor) (Waitzkin, Britt and Williams 1994). Certainly, these findings argue the need for appropriate constructions of illness for general practice care. We need to understand more about how personal, professional and societal perceptions of illness shape the health care system. Further exploration both in a more representative sample and with more detailed study beyond this level of analysis are required.
Chapter 9

Understanding satisfaction and need in relation to general practice care of patients with chronic disease and illness

An analysis of survey material

There is no clear window into the inner life of a person, for any window is always filtered through the gaze of language, signs, and the process of signification

(Denzin 1989)

Abstract

In this chapter, I explore satisfaction and need among general practice attenders with chronic conditions using quantitative approaches. I developed scales of felt need, met need and illness impact, based on interviews and a survey of people with chronic conditions.

I used statistical analysis of questionnaire to explore relationships among felt need, met need, impact of illness and belief, trust and satisfaction. Seventy per cent of attenders were highly satisfied with general practice care with little variation in satisfaction among these domains. Those with worst illness impact tended to be less satisfied with their general practice.

Self-reported psychological morbidity that paralleled physical morbidity. Felt needs for responsive and supportive personal care and co-ordinated care structures paralleled felt needs biomedical care.

Questionnaires revealed the content areas of felt need but could not explain the nature of met need nor satisfaction. However, dissatisfaction with general practitioners was more closely associated with the structure of care and technical aspects of care, rather than with the doctor-patient relationship. These findings suggest that patients chose and remain with medical practitioners with whom they have bonded and where there are perceived supportive functions in the consultations. Some may still feel a need for greater technical expertise, and particularly more supportive health care networks.

Introduction

This chapter describes the development of scales to assess 'needs' and 'outcomes' of people on long-term medication in general practice, their health care and morbidity burden. I conducted qualitative analysis of patient satisfaction and dissatisfaction and

1 Based upon survey and focus group data described in Chapter 7.
needs for care. The survey data of GP attenders (ACT, NSW and Melbourne) and ACT self-help group members, analysed in this chapter, has been described in chapter 7.

Categorising need and illness impact felt

I took guidance from the works of Glaser and Strauss (1967) and Glaser (1978) in order to apply grounded theory and social constructionist approaches to questionnaire development and the qualitative study. My approach consisted of working through analyses of discussions with key informants: colleagues and patients; analysing themes from audio-taped focus groups in the context of the literature on illness experience. This iterative process led to the development of a questionnaire and an interview schedule.

Questionnaire items, and subsequently scales, were developed to encapsulate issues in care which were significant in the focus groups and my discussions with colleagues. These dimensions of life where chronic illness was said to make a substantial impact and the felt and met needs for general practice care were transformed into Likert scales using verbatim quotes to create anchor points.

The questionnaire and scales, with room for open-ended comments, were piloted on 20 patients from my practice. I interviewed these patients about their understanding of the questions and their assessment of their relevance and general comments on the survey method and instrument. The same 20 patients were asked to complete the questionnaires again. Individual scores on the second completing were almost identical with the first completion indicating repeatability. Via this process, the scales demonstrated face and content validity and a degree of repeatability.

Construct validity was indicated by the fact that the scale reflected the major domains described in the literature, and long interviews and focus groups. The survey questionnaire completed by the first 100 consecutive GP attenders was analysed before proceeding with the full survey. Preliminary analysis indicated that the scales were reliable on the split-half method using Chronbach’s alpha and had at least face, content and convergent validity. Details of individual scale construction and reliability, and validity testing are reported below (Bowling 1990). The scale construction and reliability and validity testing were conducted on the GP attender and self-help group survey responses unless stated otherwise.

The Illness Impact Scale

The Illness Impact Scale was developed to describe an ‘outcome’ of having a chronic condition, as I decided that a cross-sectional SF-36 functional health status measurement scale was not appropriate for this study. The development of the scale was informed by two key sources intellectual property was not claimed. The first was the outcome measure de...
could not provide an outcome of having illness nor represent the outcome of having
treatment. 'A health outcome is a change in the health of an individual, a group, or
population which is attributable to an intervention or series of interventions' (AHMAC
1993). I constructed a scale using results from the preliminary study of focus groups,
interviews, and literature.

The scale aimed to measure 'how much the conditions had affected or impacted in a
negative way on individual’s lives', such that 'a sense of control was impaired'. The
scale was constructed as the sum of scores over seven items. Respondents were asked to
score the degree to which 'my illness has: affected my life; affected feelings about
myself; affected my family; affected my work; affected my life plan; affected my
finances; and made me a burden on others'. Scores were coded 0-10.

The scale ranged from 0-70. Original scores were reversed so that high scores reflected
greater impact of illness. This scale proved reliable based upon responses of 100 general
practice attenders. Subsequently, this was retested in the full dataset with a Cronbach’s
alpha of .94 (split-half reliability). Factor analysis using principal components analysis
showed one main factor:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Communality*</th>
<th>Factor Eigenvalue</th>
<th>Pct of Var</th>
<th>Cum Pct</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIFE</td>
<td>.74*</td>
<td>1</td>
<td>5.3</td>
<td>66.1</td>
</tr>
<tr>
<td>FEELINGS</td>
<td>.68*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LIFEPLAN</td>
<td>.74*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FAMILY</td>
<td>.81*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WORK</td>
<td>.79*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FINANCE</td>
<td>.70*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BURDEN</td>
<td>.71*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In addition, convergent validity was indicated because in fact there was a high
correlation between SF-36 scores and illness impact, presented in the results section.

The Felt Need Scales

The Felt Need Scales or expectations of general practitioner qualities scale of 13 items
were constructed in a similar manner to the Illness Impact Scales. All 13 items were
entered into factor analysis that identified three factors:

<table>
<thead>
<tr>
<th>Factor</th>
<th>Eigenvalue</th>
<th>Pct of Var</th>
<th>Cum Pct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5.42</td>
<td>41.7</td>
<td>41.7</td>
</tr>
<tr>
<td>2</td>
<td>1.39</td>
<td>10.7</td>
<td>52.3</td>
</tr>
<tr>
<td>3</td>
<td>1.18</td>
<td>9.1</td>
<td>61.4</td>
</tr>
</tbody>
</table>

Factor loading for the 13 items in the rotated factor matrix are:
Rotated Factor Matrix:

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEDICAL/TECHNICAL SKILL</td>
<td>.03</td>
<td>.33</td>
<td>.76</td>
</tr>
<tr>
<td>COMFORT/SUPPORT</td>
<td>-.67</td>
<td>.08</td>
<td>.36</td>
</tr>
<tr>
<td>LOGIC/RATIONAL</td>
<td>.21</td>
<td>.08</td>
<td>.81</td>
</tr>
<tr>
<td>ENTHUSE/BUCKS ME UP</td>
<td>.64</td>
<td>.21</td>
<td>.23</td>
</tr>
<tr>
<td>LISTENS</td>
<td>.66</td>
<td>.08</td>
<td>.39</td>
</tr>
<tr>
<td>COORDINATES CARE</td>
<td>.22</td>
<td>.60</td>
<td>.37</td>
</tr>
<tr>
<td>FRIEND I COULD TURN TO</td>
<td>.68</td>
<td>.47</td>
<td>-.07</td>
</tr>
<tr>
<td>SPECIALIST LIAISON</td>
<td>.20</td>
<td>.82</td>
<td>.02</td>
</tr>
<tr>
<td>TEAM MEMBER/MANAGER</td>
<td>.16</td>
<td>.86</td>
<td>.18</td>
</tr>
<tr>
<td>AVAILABLE IF NEEDED</td>
<td>.43</td>
<td>.52</td>
<td>.19</td>
</tr>
<tr>
<td>OFFICE STAFF SUPPORTIVE</td>
<td>.63</td>
<td>.27</td>
<td>.25</td>
</tr>
<tr>
<td>WILLING TO BE MAIN DOCTOR</td>
<td>.72</td>
<td>.24</td>
<td>-.07</td>
</tr>
<tr>
<td>GOOD COMMUNICATOR</td>
<td>.49</td>
<td>.04</td>
<td>.88</td>
</tr>
</tbody>
</table>

Therefore three scales were constructed around the three factors because the percentages of variation explained were all around ten and above.

Factor 1: 'GP providing support functions including a supportive doctor-patient relationship';

Factor 2: 'GP providing a supportive care structure including care co-ordination and access' and

Factor 3: 'GP technical biomedical competence and clinical skills and including communication'.

Thus the items had the following loadings:

- a supportive doctor-patient relationship
  - willing to be my main doctor',
  - a good listener',
  - a friend I could turn to,
  - provides comfort and support,
  - provides enthusiasm,
  - friendly office staff.

- supportive care structure
  - team member who managed my care,
  - good relationship with specialist,
  - available when needed,
  - co-ordinates care.

- clinical skills
  - logical,
  - medically and technically skilled,
  - a good communicator.

Thus three scales were derived: Felt Need for clinical skills; Felt Need for support structure of care and Felt Need for supportive personal doctor-patient relationship.

The Met-Need or satisfaction Scale

The Met Need Scale aimed to measure the amount of need that was met in different dimensions of patient experiences of general practice care. These dimensions were
intended to reflect the same dimensions of the *Felt Need Scales*. Through factor analysis and principal components analysis, I demonstrated that there was only one factor. On a conceptual basis, I identified this to be *global satisfaction*.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Communality</th>
<th>Factor</th>
<th>Eigenvalue</th>
<th>Pct Var</th>
<th>Cum Pct</th>
</tr>
</thead>
<tbody>
<tr>
<td>MY GP:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WORKS TO ENSURE I GET HELP I NEED</td>
<td>.91*</td>
<td>1</td>
<td>4.41</td>
<td>88.2</td>
<td>88.2</td>
</tr>
<tr>
<td>COORDINATES MY CARE</td>
<td>.75*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LISTENS TO ME</td>
<td>.92*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GIVES ME COMFORT AND SUPPORT</td>
<td>.92*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP HONEST REGARDING MY HEALTH</td>
<td>.91*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The *Met Need Scale* was constructed as the sum of scores over all five items coded 0-10; with high scores representing greater ‘met need’ that is greater satisfaction. People had either very high levels of satisfaction or high levels of satisfaction. Scores were highly skewed towards the positive end of the scale. The scale had very good internal consistency with Cronbach’s alpha of .95. This scale, however, may not have content validity for global satisfaction as it represents: functions of support including empathy and friendship, practical support, information and appraisal; support structure including co-ordination; but not technical competence (although it could be implied). Therefore an additional three items about: continuity, specialist liaison and compliance were added. Compliance implies trust in the general practitioner’s technical and clinical skills. However, still only one factor emerged with an eigenvalue of greater than one. When forced, three factors were identified.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Communality</th>
<th>Factor</th>
<th>Eigenvalue</th>
<th>Pct Var</th>
<th>Cum Pct</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONAL GP CONTINUITY IS IMPORTANT</td>
<td>.79*</td>
<td>1</td>
<td>6.22</td>
<td>77.7</td>
<td>77.7</td>
</tr>
<tr>
<td>MY GP:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WORKS CLOSELY WITH MY SPECIALIST</td>
<td>.99*</td>
<td>2</td>
<td>.58</td>
<td>7.2</td>
<td>84.9</td>
</tr>
<tr>
<td>WORKS TO ENSURE I GET HELP I NEED</td>
<td>.91*</td>
<td>3</td>
<td>.42</td>
<td>5.2</td>
<td>90.1</td>
</tr>
<tr>
<td>COORDINATES MY CARE</td>
<td>.79*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LISTENS TO ME</td>
<td>.93*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GIVES ME COMFORT AND SUPPORT</td>
<td>.91*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IS HONEST REGARDING MY HEALTH</td>
<td>.92*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I FOLLOWED GP INSTRUCTIONS (3 MTHS)</td>
<td>.96*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Rotated Factor Matrix:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONAL CONTINUITY IS IMPORTANT</td>
<td>.67</td>
<td>.44</td>
<td>.38</td>
</tr>
<tr>
<td>MY GP:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WORKS CLOSELY WITH MY SPECIALIST</td>
<td>.30</td>
<td>.21</td>
<td>.92</td>
</tr>
<tr>
<td>WORKS TO ENSURE I GET HELP I NEED</td>
<td>.86</td>
<td>.31</td>
<td>.31</td>
</tr>
<tr>
<td>COORDINATES MY CARE</td>
<td>.77</td>
<td>.17</td>
<td>.42</td>
</tr>
<tr>
<td>LISTENS TO ME</td>
<td>.82</td>
<td>.43</td>
<td>.25</td>
</tr>
<tr>
<td>GIVES ME COMFORT AND SUPPORT</td>
<td>.86</td>
<td>.34</td>
<td>.25</td>
</tr>
<tr>
<td>IS HONEST REGARDING MY HEALTH</td>
<td>.86</td>
<td>.38</td>
<td>.21</td>
</tr>
<tr>
<td>I FOLLOWED INSTRUCTIONS, PAST 3 MTHS</td>
<td>.39</td>
<td>.87</td>
<td>.23</td>
</tr>
</tbody>
</table>
When the principal components were forced into three factors, the general practitioner instructions and general practitioner liaison with specialist provided two additional weak factors. However, I decided to stay with the original five-item scale of Met Need.

Ninety per cent of the GP attenders were satisfied to very satisfied with their general practitioner. Those with worse outcomes, although still satisfied, were slightly less so than those with self-perceived better outcomes.

Correlations, logistic regression and hierarchical loglinear models - methods

Testing scale validity

In order to test the criterion validity of the Illness Impact Scale, Met Need and Felt Need Scales, I examined their univariate correlations with the validated SF-36 measures using Spearman’s rank non-parametric correlations. The performance of the scales in multivariate analysis was also assessed. This methodology is described below in understanding Met Need.

Understanding Dissatisfaction

I decided to transform Met Need into a scale of Dissatisfaction rather than satisfaction. Met need or satisfaction scores were highly skewed to the right. Seventy per cent of the attenders were highly satisfied (in the top ten per cent of possible scores) with their general practice while 75 per cent rated their general practice to be in the top 20 per cent of the scale. This left 25 per cent who scored their general practice in the lower 80 per cent. This group were classed as relatively dissatisfied, and the sample was divided at the 75 percentile into less and more dissatisfied.

Hierarchical loglinear modelling was conducted to identify patterns of interactions of unmet Need or Dissatisfaction with health status, non-categorical illness profiles and health service use. This is reported in Table 9.2. Hierarchical modelling was used in an attempt to describe the non-linear and complex patterns in the data. Such techniques are akin to the developing of multiway contingency tables, proceeding backwards and stepwise from all possible interactions among variables in model until a best fit of 3 way hierarchical interaction is obtained. Significant one-way, two-way and three-way interactions with Dissatisfaction were identified.

In order to determine the relative explanatory ability of the key independent variables and interaction terms on the outcomes measure (Dissatisfaction), forward and backward logistic regression was used as comparative and summative techniques.
The SPSSX package for Unix Release 5.0 was employed for both logistic and hierarchical loglinear modelling.

The following variables (a summary of those in Figure 8.2) were entered into the model.

<table>
<thead>
<tr>
<th>Box 9.1 Variables entered into hierarchical models of Dissatisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ILLNESS OUTCOMES OR MORBIDITY BURDEN</strong></td>
</tr>
<tr>
<td>A. Illness impact scale</td>
</tr>
<tr>
<td>B. SF-36</td>
</tr>
<tr>
<td><strong>PERSONAL (BIOPSYSOCIAL) PROFILES</strong></td>
</tr>
<tr>
<td>C. Diagnostic and Non-categorical markers of disease(s)</td>
</tr>
<tr>
<td>D. Socio-demographic factors</td>
</tr>
<tr>
<td><strong>GP CARE IN THE PAST 12 MONTHS</strong></td>
</tr>
<tr>
<td>A. Needs, wants, expectations of GP care Felt need and Met need Scales</td>
</tr>
<tr>
<td>B. GP Care Profile</td>
</tr>
<tr>
<td><strong>OTHER HEALTH CARE NETWORK</strong></td>
</tr>
<tr>
<td>A. Range and type of health care providers</td>
</tr>
<tr>
<td>Number of specialist, allied health, other consults</td>
</tr>
</tbody>
</table>

**Hierarchical loglinear and logistic regression models of Dissatisfaction with Met Need, Felt Need and Illness Impact Scales with six SF-36 domains**

Hierarchical loglinear and logistic regression modelling was conducted to determine relationships between the scales developed for the study: *Dissatisfaction* with GP care, *Felt Need in relation to general practice care* and *Illness Impact Scales* the six SF-36 domains and other study variables. Variables were grouped according to the model described in Figure 8.2. Initially robust and crude patterns in the data were explored with hierarchical loglinear models of the key variables dichotomised. Dichotomisation was chosen in order to adequately explore up to three-way interactions among eight variables because the total sample was only 294.

**Results**

**Participants Felt Need or expectations of general practitioners**

Scores on all items of each of the three scales of *Felt Need in relation to general practice care* were examined. In descending order of importance, average scores out of five possible on each scale were:

1. 'clinical skills' biomedical and cognitive - average scores 4.68 (CI 4.45-4.88)
2. 'supportive functions' in doctor-patient relationship average scores 4.46 (CI 4.36-4.53)
3. *providing/co-ordinating 'supportive care structure' average scores 4.3 (CI 4.20-4.39)*
Correlations

The five study derived scales: general practice Dissatisfaction; Illness Impact Scale; Felt Need for clinical skills; Felt Need for support structure of care and Felt Need for supportive personal doctor-patient relationship were correlated with the ‘gold standard’ SF-36 measures. Continuous rather than dichotomised variables were used. Lower general practice dissatisfaction or greater satisfaction was significantly correlated with having better status of self-rated health, less social limitation due to illness, and better physical function and role function. Felt Need for clinical skills did not vary by SF-36 status. Being worse in all SF-36 measures strongly correlated with greater illness impact, and a greater Felt Need for support structure and a supportive doctor-patient relationship. These correlations suggest both convergent validity of the scales and concurrent validity with established SF-36 measures.

Worse Illness Impact Scale scores were also highly positively correlated with the author’s personal assessment of life-threatening and disabling in relationship to the disease and service-use profiles of the two questionnaires using the clinical judgement of an experienced general practitioner. This process was described in the methodology in Chapter 7.

<table>
<thead>
<tr>
<th>SF-36 scores worse to better health status</th>
<th>GP- Dissatisfaction (Unmet need) (higher - lower)</th>
<th>Illness Impact Scale (less to more impact)</th>
<th>Felt Need for clinical skills (low-high)</th>
<th>Felt Need for supportive dr-pt relationship (low-high)</th>
<th>Felt Need for Support Structure (low-high)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-rated health</td>
<td>.14</td>
<td>-.57</td>
<td>-.09</td>
<td>-.18</td>
<td>-.15</td>
</tr>
<tr>
<td></td>
<td>N( 284)</td>
<td>N( 272)</td>
<td>N( 291)</td>
<td>N( 291)</td>
<td>N( 290)</td>
</tr>
<tr>
<td></td>
<td>Sig .02</td>
<td>Sig .00</td>
<td>Sig .13</td>
<td>Sig .00</td>
<td>Sig .01</td>
</tr>
<tr>
<td>Mental Health</td>
<td>.02</td>
<td>-.47</td>
<td>.03</td>
<td>.03</td>
<td>-.13</td>
</tr>
<tr>
<td></td>
<td>N( 283)</td>
<td>N( 270)</td>
<td>N( 289)</td>
<td>N( 289)</td>
<td>N( 288)</td>
</tr>
<tr>
<td></td>
<td>Sig .71</td>
<td>Sig .00</td>
<td>Sig .61</td>
<td>Sig .63</td>
<td>Sig .03</td>
</tr>
<tr>
<td>Social limitation due to illness</td>
<td>.13</td>
<td>-.57</td>
<td>.06</td>
<td>-.12</td>
<td>-.19</td>
</tr>
<tr>
<td></td>
<td>N( 284)</td>
<td>N( 271)</td>
<td>N( 290)</td>
<td>N( 290)</td>
<td>N( 289)</td>
</tr>
<tr>
<td></td>
<td>Sig .03</td>
<td>Sig .00</td>
<td>Sig .27</td>
<td>Sig .04</td>
<td>Sig .00</td>
</tr>
<tr>
<td>Physical function</td>
<td>.14</td>
<td>-.56</td>
<td>.06</td>
<td>-.12</td>
<td>-.13</td>
</tr>
<tr>
<td></td>
<td>N( 284)</td>
<td>N( 272)</td>
<td>N( 291)</td>
<td>N( 291)</td>
<td>N( 290)</td>
</tr>
<tr>
<td></td>
<td>Sig .02</td>
<td>Sig .00</td>
<td>Sig .33</td>
<td>Sig .05</td>
<td>Sig .03</td>
</tr>
<tr>
<td>Pain</td>
<td>.06</td>
<td>-.55</td>
<td>.07</td>
<td>-.13</td>
<td>-.13</td>
</tr>
<tr>
<td></td>
<td>N( 284)</td>
<td>N( 271)</td>
<td>N( 290)</td>
<td>N( 290)</td>
<td>N( 289)</td>
</tr>
<tr>
<td></td>
<td>Sig .29</td>
<td>Sig .00</td>
<td>Sig .22</td>
<td>Sig .03</td>
<td>Sig .03</td>
</tr>
<tr>
<td>Role function</td>
<td>.12</td>
<td>-.56</td>
<td>.02</td>
<td>-.14</td>
<td>-.18</td>
</tr>
<tr>
<td></td>
<td>N( 284)</td>
<td>N( 271)</td>
<td>N( 290)</td>
<td>N( 290)</td>
<td>N( 289)</td>
</tr>
<tr>
<td></td>
<td>Sig .05</td>
<td>Sig .00</td>
<td>Sig .79</td>
<td>Sig .02</td>
<td>Sig .00</td>
</tr>
</tbody>
</table>

Table 9.1: Spearman correlation coefficients of six SF-36 domains with met needs, felt needs and illness impact scales based on a study of 294 general practice attenders. (Significance levels (p values) based on 2-tailed tests of significance.) All variables were entered as continuous. N= number of patients in each correlation.
Understanding patterns of dissatisfaction

Table 9.2 identifies patterns of significant interactions among Dissatisfaction; Illness Impact Scale; Felt Need for clinical skills; Felt Need for support structure of care and Felt Need for supportive personal doctor-patient relationship and the six SF-36 domains using hierarchical loglinear modelling techniques. For example, the first line in table 9.2 indicates that there was a statistically significant 3 way interaction among Dissatisfaction; Illness Impact Scale and Felt Need for support structure of care. Not only is there a significant interaction among all three variables, because it is hierarchical all 2 way interactions are significant and all variables on their own have a significant interaction with each other. The specific SF-36 scales that form a significant interaction are listed in brackets under the asterisk.

Tables 9.3, 9.4, 9.5 and 9.6 report all significant interactions between other key variables described in Box 9.1 with each of Dissatisfaction; Illness Impact Scale; Felt Need for clinical skills; Felt Need for support structure of care and Felt Need for supportive personal doctor-patient relationship scales in turn using hierarchical loglinear modelling. Convergent validity of the met and felt needs measures were confirmed by these patterns. Dissatisfaction was highly interrelated with general practice usage patterns and the three types of Felt Need. Felt Needs for clinical skills interacted with GP visits, other GP characteristics and Dissatisfaction. Only Felt Needs for support structure (including co-ordination) and Felt Need for a supportive doctor-patient relationship (functions) showed significant interactions with the patterns of service use, other than general practice. Interestingly, more Felt Needs for a supportive doctor-patient relationship was associated with attending a community health centre and being in inner-city Melbourne. Having had an admission or more allied health and specialist consultations, was associated with greater Felt Needs for a supportive structure of care. Having more specialist consultations and attending physical (e.g. physiotherapist) rather than psychological or social allied health professionals (e.g. social worker or occupational therapy), was associated with a greater Felt Needs for a supportive doctor-patient relationship.

In order to develop a ‘summative’ model of greater Dissatisfaction, all significant terms from the loglinear models in Tables 9.3 to 9.6 were entered into a logistic regression model reported in Table 9.7. The SF-36 and illness impact scores were entered as continuous variables in order not to lose the detail of their scales. Other variables were left as dichotomous. Initially, a backwards stepwise regression was conducted to select the best explanatory terms, then a final fixed model was run with all significant terms. Those with greater Felt Need for a support structure had an OR of 5.55 of being more likely to have greater Dissatisfaction. The effect of practice stability depended upon the number of GP visits. Patients with less than 10 visits per year were dissatisfied where
the main GP was relatively new. Patients who attended more frequently were more likely to be dissatisfied in practices where the main GP had been present for more than 2 years.

<table>
<thead>
<tr>
<th>Significant Interaction</th>
<th>Dissatisfaction</th>
<th>Felt Needs for:</th>
<th>SF-36 scales (worse scores)</th>
<th>Illness Impact (greater)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant interactions in the same model involving GP dissatisfaction</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 way **</td>
<td>**</td>
<td>**</td>
<td>**</td>
<td>**</td>
</tr>
<tr>
<td>3 way **</td>
<td>**</td>
<td>**</td>
<td>**</td>
<td>**</td>
</tr>
<tr>
<td>2 way *</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>(Physical function)</td>
</tr>
<tr>
<td>2 way *</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>(Self-rated health)</td>
</tr>
</tbody>
</table>

| **Significant interactions in the same model not involving GP dissatisfaction** | | | | |
| 3 way ** | ** | ** | ** | ** |
| 2 way * | | | | (Self-rated health) |
| 2 way | | | | (Mental health) |
| 2 way * | | | | (Self-rated health) |
| 2 way * | | | | (Role function) |
| 2 way | | | | (Pain) |
| 2 way | | | | (Physical function) |
| 2 way | | | | (Self-rated health) |

The five study derived scales and the six scales of the SF-36 were entered into the hierarchical loglinear model as dichotomised variables. All were dichotomised at their median value except for Met Need which was dichotomised at the 75th percentile vs 25th percentile ie rating your doctor on average less than eight out of ten on the each scale item.

* indicates a statistically significant two-way interaction. ** indicates a statistically significant three-way interaction. Terms that indicate an interaction between SF-36 measures are not included in the Table.

The Iterative Proportional Fit algorithm converged at iteration 0.

The maximum difference between observed and fitted marginal totals is .157 and the convergence criterion is .250

Goodness-of-fit test statistics: Likelihood ratio chi square = 31.69342 DF = 45 P = .933;
Pearson chi square = 28.84916 DF = 45 P = .971.

**Table 9.2: Hierarchical loglinear models of interactions among Dissatisfaction, Felt needs, Illness Impact Scale and SF-36 scales.**
<table>
<thead>
<tr>
<th>GP service and usage patterns</th>
<th>GP Dissatisfaction</th>
<th>Felt Need for Clinical Skills</th>
<th>Felt Need for Support function</th>
<th>Felt Need for Support structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of GP visits in past 12 months</td>
<td>** Practice stability</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Number of GPs consulted or doctor-continuity</td>
<td>** Doctor Gender</td>
<td>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice Stability (GP continuity 2 years)</td>
<td>** Community health centre vs private practice</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 9.3 Hierarchical Models of Dissatisfaction, Felt Needs for clinical care, supportive relationship and support structure and GP service and usage patterns in 294 general practice attenders.

<table>
<thead>
<tr>
<th>Health Service use in past 12 months</th>
<th>GP Dissatisfaction</th>
<th>Felt Need for Clinical Skills</th>
<th>Felt Need for Support function</th>
<th>Felt Need for Support structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of specialists seen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of specialist consultations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of allied health professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical vs psychosocial health professionals</td>
<td>**</td>
<td>** Physical vs psych professionals</td>
<td>** Allied health professionals</td>
<td>**</td>
</tr>
</tbody>
</table>

Table 9.4 Hierarchical Models of Dissatisfaction, Felt Needs for clinical care, supportive relationship and support structure and health service use in 294 general practice attenders.

<table>
<thead>
<tr>
<th>Non categorical disease characteristics</th>
<th>GP Dissatisfaction</th>
<th>Felt Need for Clinical Skills</th>
<th>Felt Need for Support function</th>
<th>Felt Need for Support structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission in past 12 mths</td>
<td></td>
<td></td>
<td></td>
<td>*</td>
</tr>
<tr>
<td>Number of medical conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of repeat prescriptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 9.5 Hierarchical Models of Dissatisfaction, Felt Needs for clinical care, supportive relationship and support structure and non-categorical disease characteristics in 294 general practice attenders.

<table>
<thead>
<tr>
<th>Personal characteristics</th>
<th>GP Dissatisfaction</th>
<th>Felt Need for Clinical Skills</th>
<th>Felt Need for Support function</th>
<th>Felt Need for Support structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agegroup</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living arrangements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geographic location-urban, rural, innercity</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 9.6 Hierarchical Models of Dissatisfaction, Felt Needs for clinical care, supportive relationship and support structure and personal characteristics in 294 general practice attenders.

Tables 9.3, 9.4, 9.5 & 9.6: Hierarchical loglinear models of variables in categories described in Figure 8.2 with Dissatisfaction and Felt Needs dichotomised at the median. Each column variable is separately modelled with all row variables in a category. All categories and variables entered into the models are displayed and those that demonstrated significant two-way interactions are indicated with one asterisk*. Three-way interactions are indicated by **and the third interaction term described.
Significant predictors of greater GP dissatisfaction

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Adjusted Odds Ratio</th>
<th>95% Confidence interval</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact of Illness (greater vs lesser)</td>
<td>1.07</td>
<td>1.02-1.14</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical function (worse vs better)</td>
<td>1.03</td>
<td>1.00-1.12</td>
<td>0.03</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt needs for support structure (greater vs lesser)</td>
<td>5.55</td>
<td>1.03-12.5</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP service and usage characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GPs consulted in past 12 months (more than one vs 1)</td>
<td>8.02</td>
<td>7.46-8.42</td>
<td>0.00</td>
</tr>
<tr>
<td>*Practice stability for those with 1-9 GP visits/year (main GP present for 2 years+ vs &lt;2years)</td>
<td>0.81</td>
<td>0.05-1.21</td>
<td>0.02</td>
</tr>
<tr>
<td>*Practice stability for those with 10+ GP visits/yr (main GP present for 2 years+ vs &lt;2years)</td>
<td>11.2</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Physical function and illness impact scales are continuous variables while other variables are dichotomous.

* Indicates a significant two-way interaction of practice stability and general practice visits with greater dissatisfaction (OR 13.7, CI 10.65-15.06, p=0.002).

An alternative way of viewing this interaction term is

*GP visits in past 12 months in those whose GP was in practice for >2years (10+ vs 1-9) OR=0.26 (0.02-0.37)
*GP visits in past 12 months in those whose GP was in practice for 2+years (10+ vs 1-9) OR=3.2

Table 9.7 Logistic regression model of best explanatory variables of greater Dissatisfaction with general practitioner care in 294 general practice attenders. Variables and interaction terms derived from hierarchical log linear models of general practice dissatisfaction at each level of the model described in Chapter 7.

Discussion

Development, reliability and validity of scales of Dissatisfaction, Felt Needs and Illness Impact Scales

Dissatisfaction, Felt Needs and Illness Impact Scales were developed for the study using grounded theory principles based on interviews and focus groups. Face validity and repeatability was determined in a sample of 20. These scales demonstrated split-half reliability and face, criterion and convergent validity on the first 100 cases which was verified by analysis of the full 294 cases.

The question arises as to whether established scales such as the Sickness Impact Profile scale should have been used rather than developing new scales with limited evaluation. The advantage of such scales is that they have an ‘international’ point of reference, the disadvantage is that they may not actually reflect local needs. Comparisons with gold standard scales could be made in the future and evaluated further in other studies. Scales of met and felt need by people with chronic illness for general practice care perhaps do

140
not exist. However, because of their 'grounding' and simplicity, my study-derived scales performed very well in their evaluation within the study. The Dissatisfaction scale has subsequently been used as an outcome measure in a randomised control trial and performed well. Therefore, I argue that in this study these scales can be used to understand patterns of felt and met need and illness impact in people with chronic illness.

Felt Need or expectations clustered around three separate domains, yet met need or satisfaction with current main general practice demonstrated only one domain in factor analysis. Was this a true result or an artefact? Perhaps it was the effect of questionnaire fatigue, being the final question or a problem of scale construction. However, face, content and construct validity are indicated from interviews and focus groups. Convergent validity is indicated by the fact that those with the worst Illness Impact Scale scores were likely to have greater dissatisfaction or than those who had better outcomes. Despite the care taken, the study may have omitted important domains, although this is not likely because of use of focus groups to develop themes.

Alternatively, general satisfaction or dissatisfaction may be a global perception that is independent of specific felt needs. However, greater felt needs or perceived importance of general practice clinical skills, support functions and structure were all associated with greater dissatisfaction rather than the inverse. A larger sample with a more heterogeneous pattern of satisfaction may have demonstrated three factors in met need. The interviews will investigate the themes of dissatisfaction in the next chapter.

Univariate analysis indicates that greater dissatisfaction with the general practice was related to worse health status in four SF-36 domains. Greater Felt Need for a supportive structure was significantly associated with worse health status in all six SF-36 domains. Greater felt need for supportive doctor-patient relationship in general practice care was related to worse health status in all six SF-36 domains except mental health. However, Felt Need for clinical skills did not significantly vary according to health status in simple correlations, but was shown to be significantly associated with self-rated health in logistic regression models not reported in the thesis. In the same regression, those with worst Illness Impact were more likely to either see a male GP in private practice or a female GP in a community health centre. In this chapter, Dissatisfaction was more likely to be related to seeing male GPs in hierarchical models although this did not reach significance in logistic regression.

Dissatisfaction is shown to be a complex phenomenon described by correlations, hierarchical loglinear modelling and logistic regression. It may ultimately reflect patient perceived quality of biopsychosocial care. Patients in this study, who had greater Felt
Need for a support structure were on the whole more dissatisfied. Felt need for clinical skills had a lesser association with Dissatisfaction, and Felt need for support functions in the doctor-patient relationship even less, being only a simple correlation.

Different types of models of Dissatisfaction associated with general practice usage patterns and health status are summarised schematically in Figure 9.3. Different Felt Need for general practice care, were associated not only with Dissatisfaction, and general practice usage patterns, but with complex patterns of care outside of general practice. In the summative logistic regression model, worse Illness Impact, physical function and greater Felt Need for a supportive care structure were significant explanatory variables.

**Dissatisfaction and the structure of general practice care - continuity and support**

The structure of general practice care in the form of greater practice stability or main general practitioner continuity was associated with less Dissatisfaction, while fewer general practice visits were associated with greater Dissatisfaction. However, the interaction term was interesting. Apparently, if people are in a high visit group and they have general practitioner continuity they are much more likely to be dissatisfied than if
they have less general practitioner continuity in the practice. Perhaps being 'locked into continuity' when things are going wrong, needing a lot of visits, causes more dissatisfaction than if one sees more than one main general practitioner. Perhaps familiarity breeds contempt and some long-term doctor-patient relationships become less supportive.

Perhaps people lose faith in their general practitioner or project on them cumulative hostility and frustration over a long period of chronic illness with frequent attendances if the illness is not improving. Such people may be more satisfied if they see different medical practitioners who can meet their complex and multi-faceted needs in different ways. Conversely, people who attend less frequently may be dissatisfied if they keep seeing different general practitioners. The relationship between general practitioners continuity and patient satisfaction, therefore, may reflect the complex needs of people with chronic disease. However, continuity does not guarantee either satisfaction or supportive care. This challenges any complacency that may arise from assumptions that continuity ensures adequate psychosocial support in chronic illness as suggested in chapters 5 and 6.
Chapter 10

Patient experiences of Felt Needs and Met Needs (satisfaction) in relation to general practice care

A qualitative analysis

Abstract

In this chapter, I explore satisfaction and need among general practice attenders with chronic conditions using quantitative approaches. Thematic analysis of interviews with patients on long-term medication for complex conditions supported the prominence of three Felt Needs domains of the survey findings: clinical expertise; supportive care functions in the consultations; and a supportive structure of care. Very high levels of trust and belief in their current main general practice and very low levels of dissatisfaction were common themes.

Satisfaction was found to be a complex and even a paradoxical phenomenon. People, although purporting to be highly satisfied, were apparently not getting what they said they wanted or needed (eg. technical information). Others were apparently getting what they said they did not need or want (eg. psychosocial support) and still remaining highly satisfied. Others appeared to project frustration with illness, life or personal relationships onto dissatisfaction with the doctor-patient relationship.

Perceived met need or satisfaction is a complex phenomenon that may transcend the (very important) content and function of care. Satisfaction, thus appears to be determined principally by perceptions of belief, trust and matched expectations or 'intersubjectivity' and the form of medical care. A greater understanding of the nature of satisfaction may provide general practitioners with valuable insights into the complex dynamics of the 'art of medicine' and responses to illness.

Introduction

Thematic analysis of 48 transcripts of patient interviews was conducted. (More detailed methods are described in Chapter 7.) Open coding was conducted in order to develop an understanding about what factors promoted satisfaction and dissatisfaction. The data was sorted into categories of what patients said they perceived as satisfactory or unsatisfactory interactions with their general practitioners. These elements were then categorised into clinical treatment and personal care issues, and significant themes were then identified. Themes around clinical and technical skills, supportive doctor-patient relationship functions and supportive care structures were identified that corresponded to the constructs in the quantitative scales.
The role of the general practitioner

What role do general practitioners play in the lives of people with chronic conditions? A technician treating or preventing disease, or a person supporting coping with illness? The dialogues of the patients with the interviewers reflected three major themes: clinical expertise; the nature of the personal relationship; and the structure and co-ordination of care, including access and availability.

‘Felt need for clinical and technical skills’

Ten participants clearly assessed the quality of their general practitioner based on ability to apply technical skill, which is of utmost importance. They assessed this quality by a perceived thoroughness,

George: Ah, it’s not just a visit, when you go there, when I go there it’s not just a visit, it’s a thorough examination, and I can’t see how they can do any better

successful treatment

Doreen: He instils confidence… He gives me the impression—he seems to have a common sense approach… No, he (has been visiting this patient for over 20 years)… he got me through that (exacerbation of condition) amazingly… he was brilliant. Three months it took, and together we will do it, and that is his approach.

or through external validation (by other medical practitioners) of the general practitioner’s technical abilities.

John: I am not changing my doctor… Because I am quite satisfied with him and I think he knows what is wrong with me because he has proved it by sending me to the specialists and the three of them told me the same story

However, the remainder of the participants (40) blurred the elements of technical competence with seeing the general practitioner as a supportive person, with their dedication, vigilance and personal continuity, ensuring that an adequate range of care was provided.

Ava: Yeah, I do get a lot of support… I get a lot of support from other people, but he (GP) gives you a certain amount of support. I can’t say he doesn’t, because he does. A while back there he was giving me
acupuncture, that is the reason I went to him in the first place, changed over and he was very, very good. I thought, 'Oh, well, I will stay with him now...and I have stayed with him ever since. I think that is the best way to do it, rather than chop and change back and forwards. He knows what your (warfarin) levels are and that is the way I work it there. So I am quite happy with Richard, I think. He is quite a nice person, too, in himself

Heather: Elsa (general practitioner) wasn't stereotyping me and she is also. I feel comfortable too because she is always searching. I feel as though she is always searching for solutions, particularly with women.

The strength of their general practitioner was generalism, which meant being treated as a person, not just in terms of a particular disease. Communication was highly important.

Rose: I find a GP easier to talk to (than specialists). They, they've sort of ....— they're more generalised in you know, ...it's not always just the arthritis.

Beryl: They're more generalised, interested in finding um, what might be the problem... the GPs seem to be more generally interested in your case...

Paul: Yes it's very important to have that communication. I think the GP has a big load to carry because I might strike a doctor who is on his off day and I will consign him to whatever - but I don't feel that here...

‘Felt needs for a supportive personal relationship’

A personal doctor-patient relationship was valued by all participants. Trust and continuity was paramount and building up an intimate relationship was crucial when you are ill:

Brenda: If Robert left now I'd be devastated, because I don't know any other (GP)... when I started with Robert after Angela left... I had to tell him what I had and what I didn't have I'm just too sick to go through it all again. It's like getting a new boyfriend. I thought I just couldn't be bothered.
Emotional rapport is a significant feature in the personal relationship. The following comments by participants illuminate this finding:

Alison: I could talk to her and laugh like as though she was a member of the family.

Delia affectionately claimed, at the interview close, that her general practitioner was:

Delia: crazy as a person, but a wonderful doctor.

Regarding another general practitioner, a participant said,

Alison: First of all, I like her. She is a little bit reserved, I think, but I am myself

‘Felt need for a general practice to provide a supportive care structure’

The importance of a supportive structure of care with appropriate time in the consultation or when needed, were less common spontaneous themes overall. However, they were very common amongst those 20 per cent (described in Chapter 8) who reported significant disruptive chronic illness. Time spent in the consultation is very important and its absence creates a sense of going in and out a revolving door:

Paul: Yes... If, for whatever reason, the doctor says, “This is it” and you are in, you are out... I will reject him.

Time and after-hours access are appreciated for the support and comfort they provide when given freely with dedication:

Marg: From what I remember of the last one I had, he (GP) came up home, he wouldn’t go, he was that good he would not go. And I used to say to him, ‘Your beeper’s going’, and he said, “Don’t worry about that, I am not going until you are alright”...when nine o clock came, I go to bed and ten he (GP) goes.

This is particularly so, when you have an illness, that is unstable and life-threatening; access to and vigilance by the general practitioner creates a sense of security:

Alison: I have just had to have one that is close at hand... I mean, you could ring them at any time of the day or night and they are there for
you straight away. And my new doctor... if she doesn't see me in two weeks she will ring the home and find out where I am.

Co-ordination of complex care, so that the patient felt that their care was integrated was also highly supportive:

_Marg:_ Every time the specialists do anything for me or give me any tablets or anything, they send a letter to my general practitioner and then when I go to see her she says ‘Oh, I have a letter from Dr Morris or Dr William’, or whoever it is. So they are communicating all the time.

Dissatisfaction

All but two of the sample of general practice attenders interviewed stated that they were satisfied or very satisfied with their current general practitioner, although not always with general practitioners they had in the past. However, a third participant Alison who initially expressed considerable satisfaction with her general practitioner, apparently abruptly left both her husband Brian who had chronic illness and her general practitioner (an original study participant) and moved to another town and a new general practitioner. Alison then revealed considerable dissatisfaction with both her husband and the previous general practitioner. This case was referred to in Chapter 8, because both Alison and Brian reported significantly disruptive chronic illness.

The most outspokenly dissatisfied, Carole a 35-year-old woman with a disability as a result of road trauma with active Hepatitis C and a drug user, was critical of the lack of general practitioner caring, interest and co-ordination of care at the time of her first interview, when she felt very frustrated and isolated by her disabilities. The general practitioners in the community health centre that she attended, however, made frequent home visits when requested to do so, although Carole was mobile with a wheelchair. She was self-medicating with cannabis during the first interview. At a subsequent interview 18 months later, she was much more favourable about her general practitioner and the care, and had remained with the general practitioner throughout the period. However, according to the general practitioner, nothing had changed except that Carole had formed a mostly satisfactory personal relationship with a man who also became her personal carer, and that her social isolation had been remedied. Carole revealed to the interviewer in the first interview, that at some level, she expected her general practitioner to assist her in dealing with social isolation, that the general practitioner did not, or could not, do anything about this. The general practitioner, in fact, admitted to having difficulty empathising with Carole and being confronted with her hostility and dissatisfaction, and was quite relieved when she found a satisfying relationship.
At this point, a distinction had to be made between patient and general practitioner expectations of the interaction, which may differ markedly and would seem to require a 'match' between the general practitioner and the patient in order to obtain mutually satisfying outcomes of the interaction during consultation.

Ellen was both dissatisfied and satisfied with her general practitioner. Ten years ago the general practitioner had misdiagnosed a very serious medical problem. Ellen was very ill when she got to hospital, and stated that the hospital staff were critical of the general practitioner. She remains with that general practitioner, however, because, she says she now 'always has his full attention', and he will always refer if she requests it. She has maintained a strong negotiating position, because of his mistake, and now trusts that he will always treat her with utmost care. The general practitioner admits to a sense of irritation and tension with this patient, but says he could not abandon her after all these years, and actually had some affection for her.

Medical arrogance, and apparent lack of caring or rejection, was the third source of dissatisfaction that two patients described about previous general practitioners (but no-one described in relation to their current general practitioners).

Roger: 'Some doctors are that high and mighty you can't talk to them. If you say anything to them, they'll treat you like dirt...

Paul: . . . I've had very caring people(GPs), and I've had people who don't give you any - I mean, they could be very caring people, but they are just not communicating - I have found amongst men that tends to be the case, that they are not approachable, but Doctor X (GP) was eventually more approachable, because I think I demanded it. I think I was becoming very assertive because I was panic stricken...

The apparently satisfied Alison who subsequently revealed considerable dissatisfaction, described a respect for the technical competence and supportive structure of care provided by her general practitioner, but disliked what she regarded as a complete disregard for her personal difficulties in living with illness. Alison abandoned Dr B, who could neither cure nor understand her pain. She moved to a female general practitioner who could not cure, but understood not only her disease, but her personal and sexual problems:

Alison: I could go to him about my illness, what was wrong with me, but if it was the personal side of life (illness was interfering with
marital relations) it was just “you need hormone replacement therapy”
and I just felt the communication broke down

The accusation from the patient was not related to a lack of cure, but to a lack of understanding about how chronic illness affected her. Dr B did not accept her subjective experiences of feeling chronically ill and anxiety about dying, the guilt of being sick, not responding to treatment and failing in the social role of wife.

Understanding Met Needs or Greater Satisfaction

Participants in the study were much more forthcoming in their praise than criticism of general practitioners. Satisfaction levels were comparable with the survey results. It is possible that participants were reluctant to criticise the care and or treatment provided by general practitioners for a number of reasons. A range of possibilities were thus explored.

In this particular study, the general practitioners were of a high calibre (a bias which may account for the doctors’ willingness to join the sample of practitioners: they feel they have nothing to hide and are open in their communication). The bond between general practitioner and patient, which is strengthened through continuity, is such that the participant may feel disloyal if they offered criticism of their care and or treatment. Alternatively, such bonds maybe based upon mutuality and shared decision-making in the consultation, that in some cases may lead to the lowered vigilance on the part of the general practitioner and excessive responsibility to be placed upon the patient. As evident in the following quote, patients rightly or wrongly assume a level of responsibility for the care they receive from their general practitioner.

John: People are inclined to think if you are under one general practitioner for too long they get used to you and they don’t pick up certain things. But then I think that is your own fault because you are not explaining to them.

The social status of the general practitioner may also account for the participants’ reluctance to criticise, that is the perceived notion that it is bordering on the sacrilegious to criticise such an esteemed, altruistic figure. Self-blaming by participants for less than satisfactory outcomes may be an alternative to pointing the finger at the general practitioner.
Enid: And, oh, sometimes doctors I think, when they have known you a long time, get a bit lax...(recalls the time she was misdiagnosed by her GP)...So we talked about that and he was oh, sort of, you know...well he realised sort of that he had done the wrong thing. But everybody said to me, "Don’t go back to him!", but in a way I felt that possibly if I had of had the right symptoms, you know, it would have been easier for him...

The participant’s continued reliance on the general practitioner may heighten their sense of vulnerability (particularly for participants who were not convinced that the information they disclosed to a confidante, such as the interviewer, would remain confidential).

Enid: Most people are frightened to say (what they want) to the doctor.

Interviewers noticed a reluctance to focus on negative outcomes and appear ungrateful for all the good that the general practitioner has done. This perception appears in the following participant who, incidentally, seemed to accept ‘her lot’, rather than expecting the general practitioner to have a medical-technical solution.

Annette: I have been bad, I should have realised what the problem was and then he could have helped me.

In fact, Annette seems to take on considerable self-blame rather than blame the general practitioner.

Finally, wanting to find the right general practitioner and an apparent need to believe that one had the best general practitioner and specialists, whether found by accident or design, was a dominant theme throughout the interviews. People had to trust their general practitioner’s management and to like them in order to obtain support through trajectories that involved major interventions in serious conditions, the use of potent drugs, and multiple health-care scenarios. Those who were seriously dissatisfied with general practitioner care, and or treatment (in any of the three domains), could move on to general practitioners with whom they were satisfied. This phenomenon brings to mind the three virtues of faith, hope and charity which may provide the form for the healing or therapeutic relationship.
Deborah: I hear people that say they change their doctor because they are not satisfied. But I have had no reason not to be satisfied. He has always backed up whatever has gone wrong...

Clearly, some sort of compromise in expectations and a balancing 'process of negotiation' takes place at consultation. When the general practitioner care satisfies the patient's perceived overriding needs (those most important to the patient in content, functions, or form of the relationship) patients are likely to be satisfied. This is regardless of how minor or insignificant these needs may be perceived by the general practitioner or others external to the relationship. Despite the following participant voicing a need for more information regarding her treatment, she has expressed high satisfaction in her treatment overall. An analysis of this data is potentially confusing if one does not consider the numerous reasons for such diversity of perception between patients and even within a particular patient.

Delia: Yes, I think I could have got more medication and learned more about my asthma.

There was an apparent contradiction in information derived from the participants regarding their care. What some participants said they wanted or got from their general practitioners, was not necessarily what they said they received. An example of this is the statement by one participant with a debilitating chronic illness, who virtually denied the need for emotional support from his general practitioner, stating that emotional support was obtained from elsewhere. Dr R stated in his interview that in fact, this patient has required extensive emotional support from his general practitioner, but had for some reason decided to block out this state of perceived vulnerability, for what ever reason. The general practitioner believed that the participant had, 'chosen not to remember any of this'. Of course this is the patient's prerogative.

This interaction heightens the point raised in Chapter 2 about social support (Thoits 1995). Apparently, supportive functions and social network structures may not be supportive, unless they are perceived to be so by the recipient. Support and patient satisfaction are as much social constructions as illness. The need to maintain a positive self-image identified in Chapter 8 may lead to a reluctant acceptance of supportive actions, and a dissatisfaction with or denial of the need for the support.

One participant stated that she did not feel vulnerable, though her action in seeking reassurance from her general practitioner regarding the possible recurrence of a tumour
seems to contradict this. Furthermore, the situation highlights how language can curb people’s responses. She may not wish to admit or acknowledge vulnerability even to herself, let alone an interviewer. Her disclosure, however, regarding the fear of the tumour returning points to the participant as indeed feeling vulnerable and reliant upon the general practitioner’s reassurance for peace of mind and a sense of control:

Majorie: I asked him (GP) … he says that it is only superficial and I always ask him, “has it gone further?”, and he says “No”.

Participants perceptions, like those of everybody, change and are experientially based. All experience is unique, and what a patient may believe is necessary treatment or care at one point, may change at another. The participant’s criteria for satisfactory general practice consultations and personal outcomes of illness will be based on a wide base of experience gathered over that participant’s life and it will include the experiences of others with whom they have exchanged opinions.

History is always recorded from someone’s perspective. Who is in a position to say who possesses the more accurate picture of how things were or are for patients. The salient point is the existence of a myriad of possible reasons why participants may perceive in a particular way. Access to this information would greatly assist general practitioners to ‘get into the shoes of’ their patients and heighten their understanding of their patients’ needs.

Conclusion

Needs and satisfaction related to GP care

Through questionnaires, described in chapter 8, patients reported three main domains of Felt Need (identified using factor analysis) in descending order of importance: medical and technical skills which included communication; responsive and supportive personal care functions: empathic friendly, a listening general practitioner who provided personal continuity with caring staff; and thirdly, a supportive care structure, a general practitioner who coordinated care and related well to other professionals, and was available when needed. These themes were identified in both qualitative and quantitative studies. Different patterns of ‘felt need’ in relation to the general practitioner were associated with types of illness impact, health status and clinical care. Felt Need for clinical skills was ranked most important in the survey. Felt need for support functions were associated with the number of general practice visits, attending community health centres versus private practice, and attending allied health professionals who provided psychosocial inputs. Types and degree of need appeared to
vary with geographic location. In interviews, the different types of need were generally not discrete with considerable overlap in patient talk.

Satisfaction or Dissatisfaction with GP care was a complex phenomenon. The sources of dissatisfaction were: technical care; supportive functions in the doctor-patient relationship; and a supportive care structure, and appeared highly dependent on the social context. Yet, the majority of general practice attenders reported being highly satisfied or satisfied in both the questionnaire study and in interviews. Compromise, negotiation and trade-offs between different elements for care were clearly evident in the thinking of patients. However, ultimately in a fee-for-service system, one either stays or goes. If one stays, cognitive dissonance appears to operate in relationship to satisfaction. At least in the fairly dramatic case of Alison, while she was with Dr B and husband, she needed to, or wanted to, believe in the care of Dr B. However, at a certain point, the whole pattern of relationship broke down and considerable unhappiness emerged with Dr B and her husband.

Those most dissatisfied in the interviews had significant illness impact and poor physical health, similar to the survey participants. There are several explanations for this. A frustration with the inability of the general practitioner to diagnose and treat the disease process more successfully is highly likely, although denied in interviews and not strongly demonstrated in quantitative analysis. However, what is confirmed in the qualitative analysis is perceived inadequate personal care functions and responsiveness to the illness in the doctor-patient relationship. The importance of a supportive structure of care, particularly when illness became overwhelming, was important, but less evident in the patient talk, being the felt need most closely associated with dissatisfaction in the quantitative study.

In the quantitative study, the most dissatisfied patients had more general practitioners and fewer general practice visits. This group with greater illness, appeared to be less engaged with a general practitioner; either they lacked the desire or the skills, or they were unable to bond in a supportive way. Alternatively, they may not have made their needs felt due to time pressures, doctor-focus upon disease and treatment, or 'medical arrogance and rejection' in consultations. The phenomena of stoicism and stigmatisation discussed in Chapter 8 may be an important barrier to admitting the burden of chronic illness. This may be even more pronounced with the general practitioner, where it is both personally very important to maintain an acceptable public face, and highly reinforced by the time pressures on consultations not to complain. On the other hand, dissatisfaction may be projected onto the doctor-patient relationship from other domains of life with chronic illness. In the interviews, the one person who was frankly dissatisfied with her general practitioner was younger and significantly disabled. She
appeared to transfer dissatisfaction with her lack of an intimate personal relationship into dissatisfaction with a 'non-engaging' doctor-patient relationship. The three patients most dissatisfied with general practice care were dissatisfied with different elements; social network, support functions in the consultation and general practitioner clinical skills respectively.

Satisfaction and dissatisfaction in relation to the experienced 'quality' general practitioners in the study is a complicated and intricate phenomenon. Yet satisfaction is robust and able to withstand considerable shifts in felt needs and compromises in expectation. It appears to transcend the domains of felt need for functions of care and treatment, being more closely related to belief and trust and mutuality in the doctor-patient relationship. Satisfaction may operate in addition to, or in spite of, the perceived quality of technical care. The mind and body, and the social context of the individual with chronic illness, are inextricably linked in their needs for general practice care.
Chapter 11

Responding to chronic illness:

General practitioner narratives of chronic disease and illness care

While the goals of science and art may be said to be knowledge and beauty respectively, those of medicine are embarrassingly mundane: to cure, alleviate and prevent disease.

The Nature of Medicine. (Donald McClaren)

Abstract

General practitioners, in this study, constructed chronic disease as a phenomenon which required prevention, control or management through medical care and patient self-care. Diabetes was the archetypal chronic disease, with key components of prevention and self-management through self-regulation. The general practitioners described a lack of relevance of much biomedical evidence and process for them as generalists, yet they strove hard to maintain technical competence.

A major concern was providing the best biomedical care (although many were disappointed with the level of disease knowledge and evidence upon which to base their practice) and managing the personal demands that chronic long-term care could bring. Most described ‘patient-centred approaches to care’. ‘Patient-centredness’ manifested itself in various ways: from ‘it’s the patient’s responsibility to take control’ to ‘helping people to have the best quality of life they choose to.’ Chronic illness, on the other hand, was not a construct overtly or readily identified. Taking on a persona-centred highly responsive role was agreed by all to be difficult: some embraced it for the satisfaction of doing the best for their patients, but at financial and often personal cost. Others chose to stay with the biomedical script, particularly, if very busy and felt pressured by time constraints, while others were even irritated by personal demands.

General practitioners all saw that the basic care and skills needed were medical and technical. As a group, they acknowledged that ‘contextual concerns’ were important, and half consciously tried to meet biopsychosocial needs to the best of their ability. However, they did not articulate a common language, theoretical, evidence nor action frameworks in relation to chronic illness.

General practitioner narratives of chronic disease and illness:

‘Naming and framing illness and disease’ Perceptions of chronic care

I interviewed 23 general practitioner colleagues in the ACT, rural New South Wales and inner-city Melbourne in their consulting rooms. Initially I asked them about their
philosophy of medical care, disease and illness. Three-quarters of the group expressed a person-centred biopsychosocial philosophical perspective:

* I’m not particularly interested in medicine as sort of like a science. Probably I tend to as to like seeing people and having a follow up of people rather than the hospital environment where you’re literally treating diseases (Kelvin).

However, sometimes it requires effort to get beyond the routine and non-challenging diseases of general practice to see the bigger picture of humanity:

* I’m just trying to put the whole thing in a larger context I suppose. But I certainly don’t think just in terms of the disease, illness. Say ten people might come in one day all with sore throats and might all look just the same but their view of their own illness is different, their expectation of what they want me to do might be quite different. So I have to remember that if I think that it’s all routine and the same it is not because they are all different people (Randall).

In fact, Alwyn, despite being patient-centred summed up the most common attitude: that problem solving and diagnosis was the most interesting aspect of medical care:

* Now I mean obviously the things we (GPs) don’t enjoy, are the things you don’t think you’re going to be able to do anything about. Or they’re not prepared to improve their standard of health. and I suppose I enjoy mainly problem solving. Yeah. I enjoy problem solving, diagnosis (Alwyn).

All the general practitioners articulated resonance with the work of Strauss that ‘the narrative of their care and their personal and social life stories’ had a major impact on health and disease. However, despite enjoying the doctor-patient relationship (and perhaps pressured by the social desirability in a general practice culture of being beyond the disease-model), articulated by Kelvin as ‘I’m not particularly interested in medicine as sort of like a science’ the interest and challenge of general practice was the intellectual process of diagnosis. While accurate diagnosis and cure were the ultimate achievement, medical science sometimes had little to offer and here the art of medicine had a particular role.
I know that the science isn't always there but I would like to have as much scientific knowledge as possible so that you're putting the great advances of medicine through to people. When there aren't great advances, you just work on the art of keeping them happy. With... (laughing) what ever is around... (laughing) (Celine).

My next question was an open-ended inquiry about what were perceived as important issues and problems in managing chronic physical disease and illness (chronic care). Typically, the general practitioners constructed chronic care around the phenomenon of a disease which needed control through medical management based upon scientific knowledge.

You could probably make one of those nice boxes out of it. (laughs) you know one of those two-way tables: patient accepting/patient not accepting; doctor certain/uncertain... I mean you can be certain of your diagnosis and know what you want, but the person doesn't want to accept the treatment. You know they decide that "What's the point of giving up smoking or what's the point of treating your bloodpressure?" And then that brings in all your doubts about it. Your doubts about whether you should say "Well your blood pressure's higher than it should be, you know but you might get away with it." (laughs) (Celine).

Diabetes or vascular disease were archetypal chronic diseases, with key components of assessing, prescribing, monitoring and prevention and self-management through self-control. Half the general practitioners, spontaneously expressed views on chronic care, which centred around self-management with the general practitioner as adviser.

I give them the information that they want. And some people want more information than others and that is all I can do and I can give them information which might be along the lines of high cholesterol level is likely to give you a high chance of heart disease or something (Ruth).

When people are unable to take control of their own lives to do things for their own good, half the general practitioners reported feeling worried and or frustrated:
I mean there are people who - you bang your head against a brick wall! They'll pay no attention to anything you've said and that can be worrying. It's very frustrating. Like a large number of diabetics! - a fair number of them; I just know they'll pay no attention to their diet; or that if they'll take their medication or take the right insulin I've prescribed, it is just a matter of luck (Alwyn).

Adherence to healthy lifestyles was the mainstay of chronic disease prevention and management. But this was out of the control of the general practitioner. Five general practitioners nominated as a particular source of frustration those people whose incurable disease was the result of neglecting their own health:

You know, you get someone who's smoked his head off for 25 years and then he gets the most fearful obstructed airways disease or emphysema or whatever you like to call it, and he's so breathless he can't walk. Then he says, 'But there must be something you can do!' I say, 'Yes, I did. Twenty years ago I told you to stop smoking.' And they won't accept that. Or if they have got a malignancy which they've ignored, a lump in the breast and things like that: 'Well, there must be something you can do'. There's nothing you can do. People neglect themselves and, you know, they're begging for trouble (William).

Another frustrating group of patients, who the general practitioners cannot help, are those who cannot get well, often seen as seeking a secondary gain from illness:

And in the back pain (related to workers’ compensation) they're not going to get better. Refer them to physiotherapy and, I mean, how can they get better? They can't suddenly turn around and say, 'I'm dropping everything, I'm trying to get out of it because now I'm okay'. And you know this...(Eric).

All the general practitioners interviewed expressed satisfaction when their input improved patient outcome in some way. As a group, they saw this as their main task.

I, yes I do. This was in particular relation to diets and people who were overweight and who exercise and so on. Where some significant change in lifestyle is required. And yeah it is very, really nice to see these patients coming back in and saying 'I'm feeling terrific!' You know? 'The blood sugars have been great' (George).
However, when patients did not comply with what the general practitioners saw as reasonable advice, the general practitioners described three patterns of response. One-third took a philosophical stance, respecting the patients' freedom of choice:

Well, that's their choice really. ... I can give them information .... But whether they accept my advice or not is up to them. .... (George)

Medical care should basically make people enjoy life more I s'pose. I don't particularly look to - always look to prolonging life. And as an example of that I don't always aim to get absolutely beautiful looking cholesterol results or other results of the person who is not going to enjoy life because of it. So I think people should get more out of life because of medical care. So that's my philosophy (Ruth).

One-third believed that the patients needed to take responsibility:

Responsibility lies entirely with the patient. As I said, I can suggest, I can direct, I can prescribe, refer and so forth, but ultimately the patient's got to go and do it or take it or not it eat or start exercising or whatever.... I can't do it for them, I have no control over patients at all (Gregory).

Such frustration was particularly painful, when many years of intimate involvement with a patient had made the general practitioner feel very close to the patient. On the other hand, a close relationship that provided support could improve care:

You become very close to them and they trust you more and they'll confide in you often and they're your mates after a while. They're more than just your patients. You certainly will get better results, I think, from having a closer relationship with them. And see them regularly and maybe each time try and emphasise a different aspect and support the family, support the carers. Keep them out of institutions if you can (Adam).

The concept of the sick role and the legitimacy of patients adopting such a role (Parsons 1951) were prominent in the interviews; either overtly or as concepts buried in spontaneous talk. Such talk about the sick role also raised the issue of the responsibility of the general practitioner in assessing and even policing who was legitimately ill and what was legitimate behaviour (Gerhardt 1989). The 'sick role' has been much discussed and is widely taught to medical and other students (Armstrong 1989). (See
The patient is expected to relinquish responsibility and to step out of normal roles, but only fleetingly. The patient is not only expected to get better but to want to get better. In modern terms, this involves complying with healthy life-styles and avoiding the sick role.

If the physical problems of chronic disease are hard to manage in an effective manner, a further source of frustration (mentioned by five general practitioners) was that patients might present what are seen as emotional problems in the guise of a complex range of more legitimate physical complaints. This is known as somatising and the problem is seen as intractable but time consuming:

> When someone comes along who’s got depression and goes through a whole list of symptoms which takes you ten or fifteen minutes to even try and sort out and then finally bursts into tears and admits that they are as depressed as hell! Inevitably you’ll find they’ve been to see doctor A, B, C, D, E and F and it’s just time wasting. It would be much better spent trying to explain to them what depression is and how they can best cure it or indeed send them to a psychiatrist if they so need (William).

Other patients were seen as having more legitimate physical complaints but they faced the general practitioner with hostility. In this situation chronic disease, which does not ‘get better’ is seen as an accusation for the general practitioner and the medical system (Strauss and Glaser 1975). Dr W, a rural general practitioner in his forties, with an interest in psychiatry, tried to get ‘into the shoes of such people’:

> They’re just threatened by the whole, business of being ill,... putting their care in someone else’s (hands). Resolving these hostilities takes time, tact and patience (Randall).

The most rewarding patients were those who accepted their condition without unnecessarily taking on a sick role (Parsons 1951). In the absence of a cure, general practitioners saw as rewarding, those patients who were willing to take control of their lives and lifestyles in order to reduce their problems. The general practitioner then had a positive role helping people get more out of life despite chronic disease and the limitations of scientific medicine:

> To have the art to communicate... not necessarily the science, but the art to be able to communicate to the person what they want so that they can be happy with it (the current limitations of science) (Celine).
Dr M represents an alternative 'patient-centred' less 'biomedical-outcome' orientated perspective which was expressed by a third of the study general practitioners. They recognised that people have to live with their condition:

(It is) Unsatisfying just, telling someone with chronic asthma what is the most appropriate medication. It becomes a bit repetitive and boring. But the challenge I suppose is just beyond that. Look beyond their asthma and try and work out what factors in their social life you may be able to give them assistance in changing or manipulating or controlling. (Robert)

The scientific side of general practice is not only limited in its role, but can be repetitive and boring. Often, it is the individual nature of patients that makes things more interesting for the general practitioner. However, it is the patient rather than the general practitioner who constructs their chronic disease, illness and self-management.

Health is the way you see yourself and you come across patients with a multitude of disabilities who believe themselves to be well. You know patients with no disabilities who believe themselves to be unwell. I don’t see how you can be a consumer of health...That puts health in the class of a commodity. You pay your money or somebody pays for you and you end up quite healthy as a result (Graham).

Ultimately, however much general practitioners may help, self-management involves personal responsibility for complying with the best advice and treatment plan that can be devised and the ultimately outcomes of care:

Responsibility lies entirely with the patient. As said I can suggest, I can even direct, I can prescribe, refer and so forth, but ultimately the patient’s got to go and do it or take it or not it eat or start exercising or whatever. Some of these I can help with but I can’t do it for them... I have no control over patients at all (Graham).

In this situation there is confusion about what is a patient-centred role in general practice care. Is the role of the general practitioner to enable people to enjoy their life more now, and ignore non-adherence to disease management or prevention strategies that have scientific merit? Is the patient-centred role of the general practitioner to facilitate disease management or prevention in order to enable people to enjoy their life more later. Despite, general practitioners voicing firm support of either approach, as an interviewer, I perceived much of the conviction appeared to be superficial and an effort
to justify their predominant approach. This issue presents a difficult ethical dilemma for general practitioners.

Responding to and caring for illness

Managing chronic disease such as diabetes is dependent on the patient taking control of lifestyle factors and modifying them to achieve a good health outcome, as well as doctor competence. "It's a patient's inability or ability to accept the doctors certainty or uncertainty about disease management" (Carla). However, as diseases progress and ill-health ensues, the power of self-efficacy breaks down. People's quality of life deteriorates, but much more rapidly in those with unfavourable life circumstances and the general practitioner's most important role here, was:

*It's making some change for the better that would be better for the patient in the long term...in your judgement... (hesitantly) (Sue).*

*The supportive role. You've got to play a supportive role. You can't do everything. You got to try and support them... And see them regularly and maybe each time try and emphasise a different aspect and support the family. Support the carers. Keep them out of institutions if you can (Alwyn).*

In this situation, a good doctor-patient relationship becomes paramount. What elements in a doctor-patient relationship are important? Graham described that a good doctor-patient relationship exists when there is emotional rapport and the general practitioner is a trusted confidant:

*Oh the patient that comes in and bursts into tears....and not afraid to tell you what's going on emotionally. You know the very private things in life. And there are some people whom you've never seen before in your life who will come and tell you everything. But that's uncommon as I'm sure you realise. The person who comes in and tells you all the very private things (Graham).*

The domains of the care perceived by general practitioners to be important, correspond with the functions of social support particularly those which are informational and emotional discussed in Chapters 3, 7 and 10. However, there was uncertainty, or even guilt about the type and amount of social role that the general practitioner should play in chronic illness management. How useful is it compared to 'scientific' input? Five general practitioners expressed concerns about the boundaries of the scientific medicine and social inputs.
I mean, I’m sort of looking after her, not providing a lot of scientific input. Oh sure when she gets a urinary tract infection that’s easy, you bung her on another antibiotic but a lot of the time she comes in its sort of a bit sociable… she talks about social things and she sort of goes on and on about these things, and I don’t feel inclined to sort of shut her up, because I think that’s important for her to talk about these things. But you know, what’s the benefit of these things? (Celine).

Celine echoed the concerns expressed by Carla. What is the benefit of allowing patients to talk about issues seemingly unrelated to their disease. What issues are really linked to illness care and are legitimate ‘contextual concerns’ and what are just the product of life concerns or the life narratives of loneliness? What is the legitimate social role of the general practitioner?

On the other hand, out of the 23 general practitioners in the study, 12 emphasised interacting with their patients in a consciously open empathic style, committed to listening to and trying to resolve their patients’ problems. They were, they said ‘very attached’ to their patients:

*You cry—I mean I cry when they die. And in ten years I’ve lost a lot of oldies. And even though it’s not your fault, you always feel: is there anything I could have done better? I think most of us feel like that. … most patients know that they might need to wait up till an hour to see me, which is a bit rude but I have comfortable couches etc. If a patient wants to talk then you’ve got to do it then. And I think it caught one of my ladies, who I thought was just going to be a quick B12 injection, and she’d been to somebody’s funeral and that unleashed all her unresolved grief about her own husband dying. And that lady had been coming for nearly ten years and it’s the first time that it came out. A the next visit she said, ‘You know I hadn’t thought about this for years and thanks for listening’ and it really was important to her (Elvira).

The analysis of consultations of the study general practitioners and their patients on repeat prescriptions in Appendix 3 demonstrated that in general the longer the consultation, the greater proportion of patient talk about their illness, not what might be construed as social talk or chit chat. The patients who accessed longer consultations were more satisfied with their ability to confide in their general practitioner than those who accessed less consultation time. This finding is in accordance with the trajectory model of chronic disease (Strauss and Glaser 1975) and Howie’s work on consultation length and enablement (Howie et al. 1997). Patients’ three trajectories or pathways
through illness, disease and treatment and lifestyle are inextricably linked. Health-care workers facilitate people's coping and quality of life by attending to their narratives of their trajectories. The three narratives were integral to the patients' coping with their pain and disability, and compliance with medication and treatment regimes (Strauss and Glaser 1975). Such attention to patient biographies corresponds to theoretical models of biopsychosocial or 'patient-centred supportive care'.

Expectations of personal involvement in patient-centred supportive care can, however, become demanding. This particularly applied to seven women and two younger male general practitioners in the study. Such general practitioners, apparently perceived as being more sympathetic to patients with difficult problems, are selected by many patients with complex problems. Dealing on a day-to-day basis with distressing problems is wearing and it can, of course, articulate with problems in the general practitioners' own lives. Julia, who had been in full-time practice for 20 years, openly expressed her personal feelings. She spoke of the distress around the death of a patient in circumstances similar to those surrounding the recent death of her own father. She believed she had correctly diagnosed the life-threatening condition and referred promptly for emergency treatment, but it had been mismanaged by the hospital:

*And I was about to take a month off because I thought I was just too vulnerable and I couldn't get the distance (Julia).*

Julia, also, found it 'harrowing' to discover that a patient had not trusted her with a true account of the problems she was facing and instead presented a 'public face' of coping well.

*... she(DM) kept presenting this coping situation and I ... thought we were pretty honest with each other. But she obviously was using me as a way to present to herself how well she was coping and (the counsellor) rang me up and said, 'She is not coping very well and she doesn't want to come in and see you because she is going to break down and cry.' I was really upset about that ... So she came in and I said 'Well at least we can get frank now. Lets talk some more'. And then we started another type of relationship after that. But I hadn't perceived that I would be pushed into that corner ever (Julia).*

What constituted a good doctor-patient relationship with emotional involvement for some was very different for other general practitioners. Julia was very disappointed to learn that DM was presenting a coping and public face rather than the private face of
depression. Julia wanted to understand and support the reality of her patient's pain physical or psychological. Five other general practitioners described themselves as being open in similar terms. At the other extreme, William (quoted earlier) was very frustrated when people did not appropriately represent their private depression. William wanted to make an accurate diagnosis and somatisation with psychological symptoms masquerading as physical disease wasted his time. Interestingly, four other general practitioners spontaneously expressed similar frustrations.

In a close or long-term relationship, a general practitioner's failures can be haunting:

_We all do things wrong which haunt us... Of course I can think of two or three people whom I've sort of quite unintentionally mistreated but who sit here faithfully to this day and I just want to hide under the table when I know they are coming (Randall)._  

Especially for general practitioners in these situations, it is upsetting when patients reject their good intentions:

_Others for whom we'll do all we can and know we've done our best and made some contribution and perhaps they are so threatened by it that they just turn hostile and ungrateful and ... know I've done the best thing I can for them but some of them just remain terse and hostile and trot off somewhere else. But these are the ironies of life, aren't they? (Randall)._  

The remaining general practitioners adopted a more pragmatic approach to 'patient-centredness', acknowledging that patients' expectations could outstrip the general practitioner's ability to provide. They consciously limited themselves to trying to bring about 'some positive change' in a more detached manner, setting clear limits to what patients can expect from them and 'routinising' potentially painful issues:

_I tend not to become friends. Because I find it very difficult to treat friends. You can't help but be sad to see a patient die, whom you have known for a long time. But I guess the consolation is you can say to yourself they had the best possible life, died without pain. But I had one close friend die and that was a tragedy (Gregory)._  

William, in practice for 40 years, regarded as an elder statesman in his town, emphasised the need to adjust (switch off) or to run the risk of burning out. James, his
post-graduate training completed, also recognised the choices in the degree of involvement that needed to be made:

Many general practitioners burn out in that situation. Well their practices grow and grow and grow and become more involved and complicated. ... Different people have different ways of protecting themselves against that sort of thing. Some people practice different medicine that doesn’t allow people to become dependent upon them, ... just concentrate very strictly on the scientific illness curing side of it. Other people can do things like limit the number of patients on their books ... or make consultations or consulting hours very short (James).

General practitioners articulated widely differing views about what is supportive care in chronic illness and how to deal with the personal demands that their practical application of supportive care entails.

The pain of practice

Patient-centred approaches open up facts, fears and feelings for the patient (McWhinney 1989). What do they do for the general practitioners dealing with chronic disease and illness? The interviewer asked all the general practitioners; what was painful for them in general practice in relationship to chronic illness and how they dealt with ‘painful’ issues including death in their patients:

What distresses me is if I lose a four year old like I did this year. We had one case of meningitis which devastated the town, devastated the doctor. That really disturbs me, something that’s curable particularly like meningococcus which it was. That’s the only one, the rest of it I think you’ve got to get a bit tough and philosophical about. If an 88 year old dies of infarct that’s God’s will isn’t it? Not bad medicine (Basil).

For Basil, a general practice surgeon, the pain was the failure of his clinical skills and or the failure of disease management to help someone with a condition that was treatable with expectations of good quality of life afterwards. Although his care was disease-centred, the social context determined the degree of distress evoked when a patient died.

‘Hearing the pain’ is when you know people coming in with terrible emotional problems or unhappiness or chronic diseases getting worse and they are in terrible distress that you can’t help (Carla).
Well it's clearly distressing when you know young people with terminal illnesses, like I'm dealing with HIV, that and I guess it's just I'm just feeling their pain and I feel as if I can be quite useful in their illness. But I just feel their pain of having to cope with a terminal illness (Robert).

Carla and Robert reported that their pain of practice was perceived as ineptitude in the face of chronic disease and illness, the physical and psychosocial.

Josephine's worst pain of practice was located in the psychosocial domain; this emerged while discussing a patient who she felt was being physically abused:

Yeah. I sometimes, I sometimes get very affected by the people who I see and talk to and I try to talk to the social workers around in the building sometimes or the, yeah, the counsellors, social workers, just about what's going on. Particularly if they've got a patient in common. I talk to my husband.

In general terms I think it would - I would quite like it if we had a better system of support for each other in these situations. Sort of debriefing or just a buddy system where we could sometimes talk to people about difficult cases (Josephine).

Julia has a self-declared reputation for taking on cases rejected by other general practitioners for patient-centred care. My knowledge of Julia confirms this view and also the very high regard that colleagues and patients place on her work. This intense contact entails dealing not only with her patients' anger but her own anger at how some of her patients have been managed or mismanaged in both disease and illness realms in the past:

...I really think we need a really good debriefing system for these sorts of cases...because I'd probably utilise a lot of help (Julia).

and finally the views of Dr E again, the pain, yet privilege of helping 'friends' die:
This is a poor girl of only 45, she’s got bowel cancer and it’s now spread and there’s nothing else to offer her... I’ve been involved with her life since the very beginning. Delivered her children who are the same age as my own children. So I, yes, I mean it is painful... But in a way I feel privileged... They have all the oncology and vitamins and then get thrown back to the GP and that’s it. ‘We can’t do any more. Go’. You’re the one who’s in there at night and being cold, at all times of the day instead, holding the person’s hand. It’s annoying, but at the same it’s really very privileged. I do enjoy it actually (Eric).

Ten of the 23 general practitioners expressed similar views on the need for support and debriefing in difficult emotional cases and were those who took on the difficult ‘chronic patients’. Four other general practitioners expressed considerable relief being able to discuss particular patients with the interviewer, and the same number needed to confide in their spouses.

Some pain arises not from interactions with patients but from professional devaluation:

Yeah I have difficulty with specialists. I must admit. I think in this practice we try very hard and we use specialists mainly - not for diagnosis, but maybe for treatment and access to forms of treatment that we can’t give. Very rarely these days I think, you know, with adequate general practice training that you come across a problem that you can’t actually solve. That’s a bit annoying. And there’s a changing attitude in patients there. I love it when they come back and say, ‘Oh well I went and paid him $80 and he didn’t do any more than you did (Michael).

Friedson (1988) identified that hierarchies of medical practice place the specialists at the pinnacle with generalists at the bottom. The general practitioner does the work of problem-solving and diagnosis, yet this is no longer highly valued by the health system as measured by general practitioner remuneration. The specialists control the technology and surgical interventions that are most highly valued by the profession as a whole and the Health Insurance System Benefit Schedule 1991-1997 (HIC 1997). Cognitive diagnostic skills are valued at a lesser level, but what about illness care using a social model of health?

As stated in Chapter 2, illness care is non-specific. In current classification systems, illness does not actually exist unless it becomes a specific diagnosis such as depression. Evidence-based medicine is the ideal of modern clinical practice. Medical practice, particularly general practice, operates at the interface of two distinct modalities:
biomedical management and personal care, operationalised as the biopsychosocial model (Strauss and Glaser 1975; Rosser and Maguire 1982; Armstrong 1989). However there is little evidence to inform general practitioners about chronic illness care.

Sackett and colleagues (1996) recently defined ‘evidence-based medicine’ as ‘integrating individual clinical expertise with the best available external clinical evidence from systematic research’. ‘Clinical evidence’ is typically located in the biomedical paradigm encompassing a comprehensive pathophysiologic model. Constant evaluation of this expanding, complex yet always incomplete evidence, is needed to inform everyday medical practice. ‘Clinical expertise’, on the other hand, is ‘proficiency and judgement’ acquired by clinicians through experience. It is reflected in many ways, including ‘the more thoughtful identification and compassionate use of individual patients’ predicaments, rights and preferences in making clinical decisions about their care’ (Sackett et al. 1996). Described in these terms, clinical expertise approaches the status of an ‘art’.

The professional frustration of the general practitioners comes from knowing that the non-specific care, the holistic approach and the disease and illness management are not only crucial for better patient outcomes, but extremely demanding. This important work, that is also difficult, is not well defined and is therefore devalued. Even the process of diagnosis does not always ‘fit’ the real world of living human beings in general practice.

Well I reckon that specialists are so narrow minded. The advantage of (laughing) being narrow minded is that you locate the condition there and you ignore everything around it. Whereas general practitioners see everything. I’m so broadminded that its a disadvantage. You know, I send a person along to a cardiologist and they see them a couple of times, and they make this definite statement about their blood pressure etc. They see them; they make their diagnosis... and they send them back. Because you’re here as a general practitioner and you see more of the total person and all the other things in their life, sometimes the diagnosis just doesn’t completely fit (Celine).

The disease model and specialist classification can work very well and then is very helpful to general practitioners:
Sometimes it's fantastic, you know, you send them off and they say they've got this, this and this and you can do this and this and I'm very happy with that, that's great, that's what I want them to do, and sometimes they can, so I can just continue with my treatment and say you've got such and such a disease, and look it up in the book and know what the natural progressions are (Celine).

However, in many cases, the disease and specialist models do not work:

But sometimes I think they just look at a narrow perspective, you know, this person who has got diabetes, for example, "must lose weight, they must exercise, and must come along every four months to have blood tests" and they think that they've solved the problem. They haven't I mean how does this person lose weight, I mean, tell me... I don't know. So yeah, this is it, its much easier to be dogmatic, whereas in general practice because you're seeing such a broad spectrum of things I think its much more difficult (Celine).

The disease-based model often breaks down in general practice, however there are ways that one can respond. These include attempting to narrow the focus of care to a more disease-centred model, but even then there are contradictions in the literature that make disease-management inexact.

But of course you can narrow your sights in general practice, you know, I read an article and its says this is the treatment for something or other and then you read another one and they say something else, now what do you do? What I'm trying to do at the moment, is trying to set in mind my treatment for something or other so that its set for me, so I'll be more comfortable in... so basically I'm trying to do what specialist do; trying to compartmentalise saying I do this and this, and with time I might review and figure it out and perhaps change my management to a little degree, but that will make life much easier for me, if I've got a set plan for action (Celine).

Celine articulates well the dilemmas of general practice care of disease, recognising contextual concerns (Waitzkin, Britt and Williams 1994). Her articulated solution in the interview is to compartmentalise like the specialists to make life easier and more manageable, although the interviewer interpreted this to be a threat rather than a promise.
Time

Lack of time was identified as a major barrier to chronic disease and illness care in the preliminary focus groups. This perception was reinforced in the in-depth study.

There was a general consensus amongst the 23 study general practitioners that chronic disease patients take more time. Even in the cities, general practitioners felt pressured by the system to 'chum patients through' and 'have to spend time on minor problems, which didn't need a doctor' rather than being remunerated properly for dealing thoroughly with chronic patients. Managing complex disease and treatment was very time consuming:

They do take more time because they're multi factorial diseases. They've got problems in each system and you therefore... it's not like someone coming through with a sore toe which you can just diagnose and say there's the problem. Fix the problem and then out. You have to go through each system and make sure you're not missing something (Basil).

In addition to monitoring complex chronic disease and its often involved treatment, there are the time-consuming patient-centred and illness issues that many general practitioners may bypass, fulfilling other more immediate and less-complex care needs.

The people who see forty a day or fifty a day. And they provide a very important service also obviously. But they don't fulfil needs for some of their clients. And that's balanced by the people who spend twenty minutes or half an hour with each client. So I just think it's a very intriguing process and I don't really understand it but my ethos is that you, is that you should consider the patient first there. You should try to find out why they came and what's it's about. Rather than just that their child has a cold or whatever. But you've also got to fulfil the needs of seeing the sick kids in the day. You know? It's a balance (James).

While the workloads are not excessive, general practitioners can balance competing demands of complex time-consuming versus acute and quick turnover care. However, in many practices, particularly in rural practices where there is lack of support, large workloads took their toll on both chronic patient care and the general practitioners and their families:
Lack of time to listen, lack of time means lack of access. I think that’s... there’s just not enough hours in the day. I don’t think that’s fair on the patients but I also don’t think that’s fair on my family (Barry).

Discussion

The predominant philosophy of care articulated by the study general practitioners was the biopsychosocial model. Disease models worked when there was a clear-cut diagnosis, clear-cut treatment and the condition kept a text-book script. Most felt that the disease-centred model did not always ‘fit’ general practice chronic care. Often, there was uncertainty about scientific evidence and its validity in application in a particular case. If there was certainty, then the patient had to be able to accept the medical knowledge or else medical care was a futile exercise. The specialist model consisted of compartmentalising the patient into narrow diagnostic categories and giving clear-cut prescriptions. The general practitioner did not have the luxury of compartmentalising care even when there was a clear scientifically valid prescription for action related to a specific diagnosis. Patient-centred care in the real world meant that the disease was placed in the context of the individual, their other conditions, and their acceptance of the diagnosis.

From the general practitioner perspective, chronic disease was synonymous with common non-conflictual conditions such as diabetes, hypertension and vascular disease where issues of ‘control’, ‘self-control’ and lifestyle change dominated the discussion. Despite espousing similar patient-centred models, general practitioners varied in the degree of responsibility, they assumed for health outcomes in these situations. As there was no cure but strong indications that lifestyle change would increase longevity and defer or even compress morbidity, people had to either take their own responsibility for these lifestyle changes, in the hope of achieving better outcomes in the long-term, or find a path through life that conferred the best quality for them now, balanced against projected future needs. General practitioners had the role of solving diagnostic problems. Sometimes this was a minor role as diagnostic issues were often quite routine and the major role was informing people about their options and monitoring and facilitating their self-directed adherence to treatment regimens through informational and emotional support.

At later stages of chronic disease, when self-efficacy broke down, the supportive role of the general practitioner became more important as the burden of chronic illness increased. Disease care also became more complex with multi-system involvement and polypharmacy.
The ‘lived experience’ of the general practitioners and the extent to which it informed their understanding of chronic disease and illness emerged as a significant influence on general practitioner’s openness and responsiveness to patients’ illness needs. The general practitioners in the study were a heterogeneous group, following widely variant models, reflecting professional and idiosyncratic personal experiences rather than adherence to a strict ‘biomedical model’ of care. The general practitioners were most comfortable with problems they could solve, or at least felt they could offer something positive to the patient, taking a problem-solving rather than a disease approach. Patient-centredness and biopsychosocial care was also interpreted with considerable variation. Some general practitioners were completely open to patients’ personal issues and rearranged their time and surgeries around patients’ emotional and needs. They responded to their patients’ concerns across broad disease and psychosocial issues. These were more typically women, although some men also took this approach. Other general practitioners recognised that the broad range of issues existed but protected themselves by sticking to a biomedical script, by balancing their practice with acute cases, by selecting who they related to and how they related. Some wanted to do more, but time pressures were overwhelming, particularly in the country. At the extreme end, a few general practitioners (typically older male) admitted being irritated by somatizers, hypochondriacs, people who present with disease yet were depressed, and people who did not comply with advice and later developed serious disease. They wanted to treat clear-cut disease and felt that people who inappropriately took on the sick role or had pseudo-disease were time wasters.

People with chronic disease consult general practitioners in order to gain access to technical interventions to control physical disease and support for the difficulties that illness raises in their everyday life (Charmaz 1991). The models of chronic disease care in Chapters 8 and 10 attest that people with chronic physical disease want biomedical care as their first priority. In managing their patients, general practitioners attend to their physical disease and are drawn into the process of ameliorating the social disruption caused by illness. Social support functions in the consultation and a supportive structure of care were highly important in the patient survey.

The successful technical management of a patient’s physical disease is potentially a source of gratification for both patient and general practitioner. However, chronic disease is complex, incurable and progressive. There is uncertainty about the most effective ways of treating various stages of the disease. When control over the physical, emotional or social aspects of disease breaks down, this can represent a sense of personal failure for the patient and a sense of professional ineffectiveness for the general practitioner.
The management of chronic disease is difficult for patients and general practitioners alike. General practitioners perceived that providing biopsychosocial care entailed entering into a close relationship with patients and thus taking on some share of the patient's problems. This was a feature of the style of practice of women general practitioners more than men in the study. Faced with similar patients, the women were more open to 'contextual needs', and responsive in the emotional and social domains in order to provide a supportive relationship. But was this an appropriate role for a general practitioner (Waitzkin, Britt and Williams 1994)? One of the women expressed guilt that she was 'not putting a lot of science' into the management. Another problem this raises is that these women general practitioners in a general practice setting may bear a disproportionate share of the difficult, time-consuming patients in a practice. Chapter 5 indicates that most chronic physical disease is managed by mid-career male general practitioners with a disease-model, but that female general practitioners were more likely to document providing supportive interventions. Chapter 9 suggests that patients with complex needs who want supportive care may seek female general practitioners in community health centres where they exist to provide such care. General practitioners, who have many dealings with the wide-ranging problems of social disruption experienced by chronic disease patients, may be at risk of 'burning out' or narrowing the focus of their consultations to technical issues in order to survive.

While these experienced general practitioners demonstrated considerable understanding of the nature of illness, it was personal. Their care and models of care had been 'intersubjectively' constructed by their life and their patients were teachers. As Gregory, a study general practitioner, put it: 'they (the patients) teach us what we know'. Understanding the lived experiences of general practitioners and their understanding of illness is argued to be important, because ultimately management revolves around a personal relationship. This relationship has been shown to affect not only emotional and social, but disease-specific outcomes (Brown and Harris 1978). It is additionally argued that, while the technology of communication is important, it is the genuine personal interaction between general practitioner and the chronically ill patient over time which is the crux of the relationship, which in every case is likely to be idiosyncratic and unique. However, such supportive care cannot be adequately described, discussed, researched or remunerated if it in not more clearly defined.

The second solution to the problem of chronic disease management is a need for more avenues of support for patients outside of general practice, notably through improved welfare measures, self-help groups and community support. When problems are brought to a general practice setting, the general practitioner would then have access to others who can be consulted about appropriate social resources to which their patients can have access. Unfortunately, in a health system focused on economic stringency, such welfare
resources are being decreased rather than extended. The trials in Australia of managed care or care co-ordination for those with expensive chronic conditions may address these issues. However, there is a danger, in the commodification of services and processes, that the unquantifiable and largely unknown strengths of the current system, which includes the long-term evolutionary doctor-patient relationship, will be lost in a system based on economic costs and benefits.

The notions of social health and coping strategies in chronic illness, although implied in the interviews, were underdeveloped in the dialogues. Social support through the doctor-patient relationship could be satisfying or demanding and wearing, and its value questioned by some of the general practitioners. This is the juncture at which the next section of the thesis must commence. Given the strength of evidence concerning social health and its impact on the survival, we need to further explore consultation social boundaries and objectify 'psychosocial health assets and needs' of people with chronic illness to facilitate these needs being met.
Part 3

Addressing the problematic nature of chronic illness care
Chapter 12

Social support—an overarching framework for clinical care

Transdisciplinary linkages facilitate practice, research and evaluation

“Theory may be regarded as a broad framework for organising and ordering research, or as a collection of general concepts... directing attention... or orientation” Turner

Abstract

Ideally, general practitioners base their clinical management upon scientific evidence. The traditional clinical paradigm focuses its evidence upon the biomedical basis of practice. Dealing with psychosocial processes and contextual implementation of biomedical evidence is often deemed the 'art' of medicine and is therefore considered peripheral.

In this chapter, I examine the concept of social support as a framework to evaluate evidence related to aspects of the 'art' of medicine: specifically, the interpersonal dimension in the general practice context. I conducted a literature review based on a search of the Medline and PsycLIT electronic databases. Original and review articles of qualitative, and quantitative longitudinal, cross-sectional and meta-analytic studies on social support, the doctor-patient relationship and health were investigated.

Social support theory provides an appropriate conceptual framework for the considerable, but often ad hoc and atheoretical evidence about human relationships and health. This includes the doctor-patient relationship, medical interventions and biopsychosocial health outcomes. However, what is satisfactorily supportive, is highly specific to individuals or groups with different backgrounds at different stages of health and illness. Currently, social support research is mainly driven by empiricism. Greater emphasis upon theory construction and inductive approaches is required.

I conclude that evidence about human relationships and health and the biopsychosocial model of care can be systematically evaluated and placed in the foreground of practice. Social support offers an apt framework or meta construct for such evidence, although requiring conceptual linkages or integration of different types of theory and evidence to inform the 'art' of intervention in different contexts.
Introduction

This thesis argues that far greater emphasis be given to processes beyond the traditional medical model. A practitioner may have greatest impact on individual health outcomes in people with chronic illness with the apparently 'softer' and more difficult to measure processes of non-disease orientated physical and psychosocial care, particularly longitudinal primary care that has been defined as non-categorical in Chapter 2 (Arpin et al. 1990; Browne et al. 1990; Stein and Jessop 1991; Jessop and Stein 1994). In Chapter 2, and more specifically in a paper jointly written with Dr Chris Peterson, I have described not only the complexity of the research paradigm and discipline that can inform chronic illness care and its evaluation, but demonstrated by argument the need to integrate and incorporate these multiple perspectives to provide best quality of care (Martin and Peterson 1997). If this 'soft' evidence is not coherently described, systematically synthesised and placed in the foreground of medical thinking, practice will be driven by what is measurable and evidence-based in the current dominant paradigm: the biomedical basis of practice. The chapter demonstrates that social support constructs can integrate biomedical and physical and psychosocial care, and link the doctor-patient relationship and other support relationships in a way that is meaningful for longitudinal chronic disease and illness care.

The concept of social support provides an overarching framework for interpersonal interactions (including doctor-patient relations) at an individual functional level and in formal and informal networks. A patient-centred philosophy is implied in this framework. The lived experience of illness research provides an understanding of how people construct their illness and their healing. Such research also reflect critically on the constructions that professional, institutions and society at large place around people with chronic disease. Thirdly, the concept of enablement provides an 'outcome', and consultation length provides a marker of enabling consultation processes. In this chapter, I concentrate upon the constructs of social support as the other areas mentioned have been addressed in the previous chapters. In Appendix 4, social support guidelines for the ACT Co-ordinated Care Trial are listed among examples of outputs from this thesis. These have been developed (by the author in collaboration with a multi-disciplinary team) incorporating material presented in this chapter.

Developing a social support construct

Searches were made on Medline 1966-5 to 1997 and all PsycLIT electronic databases. A huge volume of material, with over 8000 articles linking psychosocial processes and health, and over 7000 linking social support and health was interrogated. Key words searched included social support, health outcomes, health, doctor-patient relationship, general practice and primary care. I selected key articles, book chapters and recent
reviews in order to examine social support as a conceptual framework for the interpersonal processes related to general practice care. Forty-five articles on general practice and social support from 1966-5 to 1997 were identified, but with a conspicuous lack of overt overlap among the doctor-patient relationship and social support literatures with only five such articles identified.

The 'art' of clinical expertise

The 'art' of medicine has two components: 'form' and 'content' (McWhinney 1989). Patients exhibit a responsiveness to the form of the treatment or consultation, whatever the content. The overt and covert actions and settings form the atmosphere of medical care. These include: the white coat; the atmosphere of the surgery and waiting room; the general practitioner’s consulting arrangements, the authority conveyed by medical diplomas, have a potent, but generally unmeasured impact on effective medical care. This placebo effectiveness or 'general medical effectiveness' has, in the past, been inferred to account for between 35 per cent and 60 per cent of the effectiveness of biomedicine (Moerman 1983). Form is associated with spiritual or transcendental qualities and is highly contingent upon the socio-cultural context. The form or construction of the medical ambience has not typically been subject to measurement. The content of the doctor-patient relationship and consultation processes, on the other hand, has achieved considerable research attention. It has focussed upon communication process and style, patient centredness and stages of the consultation. This work, however, is often cross-sectional and has often lacked a theoretical framework linking it to form or other social or clinical processes (Innui and Carter 1985).

Social support theories—linking social, psychological and physiological processes

An individual’s relationships with people, institutions and physical surroundings provide social assets such as intimacy, companionship, access to information and practical support. By identifying that suicide rates varied with different degrees of social cohesion, Emile Durkheim, became the father of modern social support theory (Thompson 1985). Social support can be simply defined as the availability of people on whom patients feel that they can depend (Blumenthal and Wei 1993). Currently, social support theory recognises both structural and functional elements of interpersonal relationships and social assets that contribute to the provision of support. Structural elements include the size, density, flexibility and adequacy of an individual’s network of intimates, friends, colleagues and experts. Social embeddedness describes the degree and type of bonding (such as trust) between participants. Functional elements are the actual supportive acts received (and provided) and people’s perceptions of their quality. Functions of support cover emotional, practical, informational, appraisal and companionship domains in human interactions. In practice, these functions are often
difficult to separate and usually highly inter-correlated (House and Kahn 1985). Social support models link social, psychological and physiological levels of functioning. Health is determined by the balance between social, psychological and physiological stress and the host vulnerability or resistance (assets or resources) (House and Kahn 1985; Medalie and Zyanski 1992). Various resources have a different impact in different settings.

Resources are both economic and biological, psychological and social (Feinstein 1993). Biological resources include genetic and acquired physical characteristics. Psychological resources including intellectual (perceptual reasoning, judgement and memory) and affective and emotional functioning. Socio-economic resources employment and occupational prestige, income, education and environmental resources, shape the quality of life. Adequate access to and utilisation of appropriate health care is also important. In a major review of the international literature, Feinstein (1993) concluded that material resources and behavioural factors jointly contribute to the inequalities in health outcomes between different social categories. Socio-cultural norms influence smoking, alcohol consumption and health service-use behaviours, sometimes opposing positive effects of group identity and support.

Social support and health outcomes

Social support appears to protect individuals from a variety of physical (Medalie and Gouldbouurt 1976) and psychological symptoms, mortality, (Brown and Harris 1978; Berkman and Syme 1979; Blazer 1982; House, Robbins and Metzner 1982; Weilin, Tibblin and Svardssudd 1985; Schoenbach et al. 1986; Orth-Gomer and Johnson 1987; Kaplan et al. 1988; Hanson et al. 1989) and morbidity. Survival in breast cancer correlated with the quality of personal support relationships (Greer, Morris and Pettingale 1979) and enhanced support networks (Speigel et al. 1989). In addition, social networks may protect the elderly from institutionalisation and death (Bowling 1991). A meta-analysis of nine major cohort studies, showed that the magnitude of the effect of social support variables on cardiovascular mortality was similar to variables such as blood pressure and exercise in middle-aged white males (Olsen 1992). A protective social network has been shown in several studies to be protective for cardiac recovery in both emotional and physical recovery from myocardial infarction (Moser 1994; Yates, Skaggs and Parker 1994). In contrast, a meta-analysis that looked at different populations with greater diversity of dependent and independent variables, including support measurement scales, found weak positive effects and even negative effects (Smith et al. 1994). In the same analysis, the association between availability and adequacy of supportive people with satisfaction with social support, produced significant positive effects. In Australian studies, Winefield and Katsikitis (1987) and Winefield and Murrell (1992) found people recovering from serious illness judged that
families, general practitioners and the specialists involved to be particularly important sources of support.

The doctor-patient relationship, social support and general practice care

Literature on the relationship between social support and general practice care is currently located in several areas: the importance of primary medical care in recovering from serious illness; the doctor-patient relationship; and the psychosocial characteristics and behaviour of general practice attenders with ill-defined conditions. In general, the literature does not overtly link the doctor-patient relationship with social support constructs. The importance of the primary care physician as a source of support for those recovering from major medical conditions, such as breast cancer surgery, myocardial infarction and mental illness have been detailed (Neuling and Winefield 1988). What elements in the doctor-patient relationship are supportive or healing? Kohle and colleagues (1982) and Winefield and Murrell (1992) identified informational and emotional, as well as technical components of the general practitioner-patient consultation dialogue. Stewart's (1995) meta-analysis of studies of doctor-patient interactions and health outcomes indicated that the quality of communication in the history taking and the management discussion stages of the consultation have greatest impact (better information, appraisal, empathy etc). The outcomes most affected were, in descending order of frequency: emotional health, symptom resolution, physiological measures such as blood sugar and blood pressure control, and pain control. Positive elements associated with improved health status and biomedical outcomes in hypertension, diabetes etc. were the transfer of sufficient information to patients to allow them to carry out an active role in self-care (informational support) (Kaplan, Greenfield and Ware 1989a). Patient compliance and satisfaction were positively related to successful discussion of non-medical problems in the consultation and to the ability of both general practitioners and patients to express negative emotions with reciprocal appraisal (emotional empathy and appraisal support) (Martin and Blass 1989). The odds of a satisfactory consultation increased significantly where a personal doctor-patient relationship prevailed. Satisfaction correlated weakly with the duration of the doctor-patient relationship, but not at all with the frequency of consultation (Hjortdahl and Laerum 1992). (Although a satisfactory support structure was somewhat important, the quality of the bonding or social embeddedness appeared most important (Kaplan, Greenfield and Ware 1989b).) Therefore, the doctor-patient relationship with its longitudinal component, often linked by the continuity of the problem, but ideally cemented by trust and interpersonal bonding and providing emotional, informational, appraisal, practical and friendship inputs, has the potential to provide a major social support function. Studies of the behaviour of general practice attenders have identified groups with less optimum psychosocial and social network characteristics. These general practice attenders often have ‘undifferentiated illness’ that is that their general
practitioners are unable to make specific diagnoses in relation to their problems (Balint 1977). They may have psychological or social needs (Pini, Piccinelli and Zimmermann Tansella 1995) or are frequent attenders (Falkner, Fatovich and Winkler 1987). They are likely to attend for minor illness (Corney 1990) or without appointments (Virji 1990). These studies indicate the importance of psychosocial background as well as diagnostic categories of people attending general practice.

The construct of social support provides a theoretical perspective from which to examine evidence on general practice interventions for both differentiated and undifferentiated illness. These interventions maybe actively provided by general practitioners through intervention or referral or result from more naturalistic interactions with their patients over time. However, apart from a few studies in disease-based care, the literature about human interactions and outcomes of general practice care has been atheoretical and ad hoc. There is considerable potential to integrate many existing general practice studies into a broad conceptual framework, that will allow better theory development and testing. This chapter argues that social support theory provides such a framework.

Despite the well-documented effects of the protective and restorative effects of social integration, health and social service interventions to artificially introduce social support, have often floundered or produced weak or equivocal results. This has been so in some interventions in chronic illness (Gottleib 1992; Toseland, Blanchard and McCallion 1993), while apparently more ‘naturalistic’ positive support from family, friends, and primary care physician contacts can protect and restore psychological health (Goldberg and Huxley 1992). There have been encouraging successes in breast cancer, where observational data suggests that being married, or having better primary support networks increase survival (Reynolds et al. 1994), and where enhanced psychosocial support doubled the survival time in one randomised controlled trial (Speigel et al. 1989). However, although some studies in breast cancer have shown no relationship between psychosocial support and survival (Gellert 1993) a more recent meta analysis of controlled trials confirmed a positive relationship between better support and better outcomes (Meyer and Mark 1995). Not all relationships or formal interventions that are assumed to be supportive are beneficial. Interpersonal relationships or well-meaning health or social service ‘supportive’ interventions may even be harmful (Thoits 1995). In conclusion, social relationships are strongly associated with better health outcomes in many situations. We need to know more about psychosocial processes to understand why positive support does not occur in all situations including formal interventions.

Like theories that drive biomedical interventions, contemporary social support theories have limitations. Problems of conceptualisation and definition currently limit the ability
of social support theory to inform general practice. First, we do not understand the intervening mechanisms by which elements of social interaction mediate their protective effect on health for different people, in different social contexts and disease stages. Is perceived social support and social integration a proxy for underlying personality factors that predispose to better coping (Henderson et al. 1980) which are probably stable through life (Costa and McCrae 1980; Costa and McCrae 1988; Thoits 1995)? Despite people’s innate personality characteristics and their varying perception of need for supportive professional relationships in health, all are vulnerable in ill health. Support is then needed from ‘experts’: their general practitioners and others in the health care and welfare systems. However, ‘the culture of most interventions differ strongly from the natural ecology in which normal supportive transactions for an individual take place’ (Gottleib 1992). The general practitioner and other formal health and social care providers may, in good faith, assess, provide and mobilise social resources for a sick individual, yet intimate needs may not be met, elements which engender autonomy maybe traded for those which may hasten dependency. Social interactions, which are most effective, incorporate an understanding people’s experiences, is empathic and culturally attuned to the needs of the individual. Also, practical support tasks are more effective if provided by those with appropriate resources, rather than according to the primacy of the relationship in people’s lives (Messeri, Silverstein and Litwak 1993). Because of the implications for care provision, greater understanding of support enhancement and substitution in ill-health, vulnerability and old age are needed (Thoits 1995).

The meaning of social support

It is postulated that the positive effect of social support operates by improving self-esteem and enabling an individual to exercise greater control over their physical, psychological and social environment (Mechanic 1974; House and Kahn 1985; Deci and Ryan 1987; Syme 1989). Social integration and optimised psychosocial resources act as direct or indirect buffers against stress and adverse life events (Cassell 1935; Nuckolls, Cassel and Kaplan 1972). Psychoneuroimmunological pathways and mechanisms have been hypothesised to operate to promote health (Syme 1989; Ostergren 1991; Lyon 1993). The major thrust of this work is to determine the biological correlates of social and psychological states. Major barriers have been the difficulties in conceptualising the ‘meaning’ and ‘situatedness’ or context of these states and interventions (Lyon 1993). A life event such as divorce can be a release or is devastating according to its context. Similarly, chronic illness, that may be accepted with equanimity in old age is a major disaster for an adult with pressures to perform in economic and social areas. Cumulative daily hassles may be more stressful than a significant life event, while significant relationships may vary in their ability to provide support.
Both conceptualising and measuring abstract concepts such as support, health integration and stress have been problematic. What is actually measured often determines the construct rather than vice versa. This has the effect of focusing most of the research upon the content and process of interaction, ignoring the form or individual interpretation of the social interaction. Secondly, assuming the instruments measuring health and social factors are valid and reliable, we do not understand the elements and mechanisms by which social interaction mediates its effect in biological and psychosocial domains. Also in most cases, it is difficult to have controls let alone institute a natural experiment. Causality is thus usually disputable. Illness is the stressor with recovery and adjustment the desired outcomes. These in turn are influenced by the meaning of the lived experience of illness: the varying perceptions, thoughts, feelings and acts affecting the personal and social meaning of symptoms, illness, disabilities and their consequences (Mechanic 1977). Is there pain, for example? The meaning and experience of the pain can depend on the person’s value system (what he or she views as important in life), on the surrounding context or on the secondary effects of the stressor (added life strains) as well as the biological process. Meaning can also be construed in terms of the broader socio-cultural beliefs about roles, expectations and functions in society. Concepts such as masculinity, parenting, responsibility for others and work responsibilities define the illness (Thoits 1995). Threat is also socially constructed on an individual basis.

A way forward in the problem of measurement and conceptualisation of processes that are highly subject and context dependent is to shift from mainly quantitative empirically driven research towards greater theory development. Returning to the source of social support theory and Durkheim’s original approach with more observational and theory generating research would be productive. In fact, social support research needs to link with debates in social theory and concerns with the nature of the social in modern society (Turner and Samson 1996). This could entail using transdisciplinary mechanisms (Rosenfield, 1992; Martin and Peterson 1997) incorporating social constructivism or anthropological approaches, but using commonly agreed upon social support meta constructs. This would facilitate the exploration of both the form and content of medical care and development of better evidence to inform principles and clinical practice guidelines.

Discussion

Psychosocial factors can have a significant effect on the onset of some diseases, on the course of many, and the management of nearly all. The predominant approach in medicine is to treat people with physical and chemical treatments which neglect mental, emotional and behavioural dimensions of an illness and promoting wellness. This can lead to frustration, ineffectiveness and wasted health care resources. By helping patients
manage not just their disease, but their common underlying needs for social support, coping skills and sense of control, individual outcomes and population health outcomes could significantly improve in a cost effective manner (Speigel et al. 1989; Bowling and Browne 1991). There is emerging evidence, particularly from general practice, that physicians who take adequate time can empower patients and address their psychosocial needs (Howie, Heaney and Maxwell 1995). However, the content, processes and long-term impacts of such practices need further clarification. Although health care systems cannot expect to address all psychosocial needs of all patients, clinical interventions can align with other agencies and personal networks in a reflective and systematic way. Emerging evidence on shared psychosocial and biological determinants of health should receive greater emphasis to address psychosocial needs and improve adaptation to illness.

The research on social support in human relationships, and the broader biopsychosocial model, offers a coherent framework (or meta construct) to describe the interpersonal work between general practitioner and patient and interventions. Social support and biopsychosocial models have other advantages. Medical care can be conceptually linked with the care provided by other health professionals and support provided by self-help or community groups in the context of individual personal networks. Psychosocial processes can be integrated with the biomedical and technical in outcome orientated research.

Both the assumed effectiveness of the form of Western rituals of health provision, and the content and process of the doctor-patient relationship need continual scrutiny. Unless psychosocial processes are included, evidence-based medicine will be, at best, inefficient with general practitioners predominantly working in one modality: the biomedical. Positive clinician support includes systematic, reflective and appropriate emotional, practical, informational, appraisal and even friendship components. It requires appropriate form and structures and a trusting relationship in congruence with other networks to enable people to utilise their psychosocial assets and coping skills to maintain greater autonomy and control in health and illness. At this time, there is a lack of systematic definition and evaluation of psychosocial interventions (in common with many biomedical interventions) (Sackett et al. 1996). Perhaps some processes will always evade tight definition, and retain their mystique as an 'art'. However, there is ample evidence to provide a broad framework to describe social support, and psychosocial processes and coping (Thoits 1995). There is a need for continual refinement and testing of theory. Medical care has a unique potential for benefit or harm. The dual modalities of clinical medicine: the biomedical and the psychosocial, need better evidence to guide the ‘art’ of practical implementation in different biopsychosocial contexts.
Chapter 11 identified that the lack of an action framework for chronic illness and biopsychosocial care with social models is a major drawback for general practice care. General practitioners bemoaned the lack of scientific evidence for disease care, but did not question or seek research evidence about psychosocial care. They were all, in their own idiosyncratic way, philosophically attuned with the biopsychosocial model of care. Yet their supportive processes were at great variance, demonstrating a survivalist mode of working to a greater or lesser extent. What was interesting in this study, was that in Chapter 10, it was fairly convincingly demonstrated that patients wanted biomedical management, support functions and a supportive care structure. Dissatisfaction was particularly linked with a lack of a supportive structure, followed by the need for clinical skills and lastly with support functions. In contrast, in the interview study with general practitioners, supportive care in chronic illness was located around informational and emotional support, that were judged to be painful and very personally demanding for general practitioners. I strongly contend that better operational models of support are required not only to better meet patient needs, but to organise the complex processes of support into simpler more manageable action models. The support model is argued to be appropriate for this purpose, if it is understood as being socially constructed and used as an action framework rather than a narrow prescription for action.
Chapter 13

Developing and implementing operational models of chronic illness care

Problems and solutions

Synergism, as such, is the simultaneous action of separate forces that enhance one another to produce a total effect that is greater than the sum of the effects.

*Disease in Search of Remedy, Peter Marcuse*

Abstract

Chronic illness care is difficult for general practitioners to implement because, currently, theory, practice and health systems are inadequately developed. In the process of investigating the problematic nature of such chronic illness care, I identified a range of solutions at a theoretical, educational, clinical and system level. Transdisciplinary mechanisms are needed to link fragmented theoretical approaches to understanding and responding to patients’ experiences of illness.

Social support constructs are proposed as linking constructs between disease and illness and provide an operational framework for general practice and other health and other longitudinal chronic care. The models of care of the individual general practitioner, the shape of consultations, the organisation of the practice and the funding, structure and culture of the health system all provide opportunities for a shift to optimise chronic illness care. I provide examples where my work has begun to take advantage of such opportunities.

The problematic nature of chronic illness care

This thesis investigated the nature of chronic illness and its care in general practice. The nature of chronic illness and the response of individuals, general practitioners and the wider health system is a highly complex area. I used multiple methods linking different
disciplinary approaches underpinned by social constructivism to gain an understanding about this complexity.

Chronic illness, an unpleasant bodily experience affecting quality of life, is an important concomitant of the chronic physical disease managed in general practice. Such illness involves mind, body and the environment. People have different pathways through illness influenced by the disease, the treatment and system of care and their own personal life journey. Therefore, managing chronic illness requires different approaches or paradigms of care to that most appropriate to managing disease.

Chronic illness, because it is a personal experience or perception of unpleasant sensations that interfere with daily life, is managed by the individual with support from general practice and the health system. Healing of illness involves a reconstruction of a personal internal narrative of the disease, the treatment and the life trajectory.

**Difficulties in managing both the disease and the illness**

Medical training for general practice endorses both disease and illness care based upon the biopsychosocial model. However, in this thesis, I have demonstrated that while the biopsychosocial model of care is highly appropriate for chronic illness care, it is poorly operationalised for clinical practice. Chronic illness is apparently managed by a significant proportion of general practitioners in a chronic physical disease or biomedical framework, because that is the dominant model. Chronic illness care appears to be primarily provided by a minority of sympathetic general practitioners without external support or well-defined models of care. Does this matter? My evidence is that this matters for patients, general practitioners and by implication the community and the health system. Psychosocial and physical morbidity accompanying chronic physical disease impairs not only quality of life, but also disease management and by implication, and also demonstrated in two clinical trials, encourages greater use of expensive health care resources (Browne et al. 1990; Stein and Jessop 1991). Therefore, clinical frameworks and actions for general practice care of chronic illness urgently need definition, particularly at a time of health care reform.

This thesis now addresses how important insights accumulated through the study about chronic illness care, from the literature and my empirical work, can be developed further. During the process of investigating the nature of chronic disease and illness in general practice, I have generated a series of journal articles, clinical care and educational monographs that address the operational and implementation issues that are described below in Box 13.1.
Box 13.1 A suggested schema for improved implementation of chronic illness care in Australian general practice

Implementing better chronic illness care in Australian general practice

Theory

**Illness experience, professional responsiveness and social constructions of illness in biopsychosocial domains**

Appropriate conceptualisations of the lived experience of illness and caring for illness.
Recognition of the impact of the sick role implicit in health service organisation and society in general.
Appropriate theoretical models based upon transdisciplinary evidence.
Appropriate translation and language for classification systems which describe nosological space and process as well as action frameworks for care.

**Clinical frameworks**

**Biopsychosocial care incorporating supportive interpersonal relationships, functions and supportive structures**

The practitioner

- Acquiring biopsychosocial models of illness and appropriate action frameworks.
- Recognition of the nature of classification systems and labelling in every day practice.
- Appropriate educational strategies for undergraduate, vocational training, post-graduate training and CME.
- Feedback about knowledge, attitudes and practice.

The consultation

**GP Clinical expertise**

- Management of common disease with supported management of rarer conditions.

**Interpersonal dimensions**

- Patient narratives of illness, treatment and biography.
- Supportive interpersonal relationships and 'patient-centred' functions.
- Health and personal enablement.

**Support functions**

- Assess, provide, refer for supportive care.

**Structural dimensions**

- Consultation length.
- Periodic chronic disease review and longitudinal monitoring in consultation.

The practice

- Supportive reception staff.
- Continuity/liaison/co-ordination monitors patient status outside of consultations access.
- Remuneration to support extra-consultation care eg the Better Practice Payment.

The health care system

**System - structural and network dimensions**

- Funding for care planning, care coordination, case management across sectors.
- Integrated service delivery and supportive care structure -managed or coordinated care through Divisions of General Practice.
- Promoting interrelationships among general practice, health and other systems eg social services through common models of care.

**Theory**

**Illness experience, professional responsiveness and social constructions of illness in biopsychosocial domains**

The lived experience of illness of the afflicted individual is central to chronic illness care (Strauss and Corbin 1988; Kleinman 1995; Toombs, Brand and Carson 1995).

Health and social welfare systems are driven by professional roles, rules and regulations.
that shape how the individual enacts a sick role (Strauss and Corbin 1988; Gillick 1995). The patient-centred model for general practice endorses the centrality of the individual’s lived experience in the doctor-patient relationship in an individual consultation and in relationship to health outcomes (Hollnagel and Malterud 1995; Stewart 1995; Stewart, Brown and Weston 1995). However, patient-centredness on a continuum in chronic care is less well understood and is without a framework for implementation in general practice and the health system. This thesis has identified the construct(s) of social support as appropriate model(s) for general practice chronic illness care to complement disease management. Social support itself encompasses many concepts such as functional, structural and perceptual or experiential components. Autonomy, self-mastery, self efficacy and a sense of coherence are important outcomes of support, promoting better coping (Antonovsky 1993; Squier and Kaplan 1996). American paediatricians have developed a system of terminology for such supportive care called ‘non-categorical’ or non-disease based care (Martin and Nisa 1996).

Social support theory provides an appropriate conceptual framework for the considerable, but often ad hoc and atheoretical evidence about human relationships and health, and actions in clinical practice. This includes the doctor-patient relationship, medical interventions and biopsychosocial health outcomes. However, what is satisfactorily supportive, is highly specific to individuals or groups with different backgrounds at different stages of health and illness. Currently, social support research is mainly driven by empiricism. Greater emphasis upon theory construction and inductive approaches are required.

Evidence about human relationships and health must be systematically evaluated and placed in the foreground of practice to achieve better contextual responsiveness and outcomes in clinical care. Social support offers an apt framework or meta construct for such evidence, although requiring conceptual linkages or integration of different types of theory and evidence to inform the ‘art’ of intervention in different contexts.

However, social support together with quality of life and illness, are subjectively constructed and only partially fit the objective scientific measurement paradigm as demonstrated throughout the thesis. Therefore, in order to deal with disease and illness using support as the construct to inform the actions and intersubjective nature of biopsychosocial care, general practice needs transdisciplinary approaches. Otherwise, the biopsychosocial model of care will remain theoretical and disease models will continue to dominate in practice.

Appropriate theoretical models based upon transdisciplinary evidence with appropriate synthesis, translation and language for action frameworks are thus required, given the
broad range of different disciplinary models (Martin and Peterson 1997). I argue that social support constructs provide an action framework for chronic illness care. Support constructs can organise the general practitioner’s patient-centred responses to the patient’s illness, treatment and life narratives in the consultation and beyond. Support constructs also provide an appropriate theoretical base for the biopsychosocial frameworks and actions of care co-ordination, case management and ‘non-specific’ or non-categorical care. (See Appendix 4 for references to Social Support Guidelines for the ACT Care-co-ordination Trial, and submissions to the GP Strategy Review, 1998).

Chronic illness care needs to respond to the personal experiences of illness and trajectories through disease states and health service provision and their meanings. The patient-centred-model provides a theoretical underpinning for general practice care. Yet, it has not been fully developed for chronic illness and disease care.

We need to categorise what is currently ‘non-specific’, not just naming states of health and quality of life for researchers, but to further develop frameworks that are operational for clinical action. Such frameworks must provide appropriately broad social constructs that assist practitioners to be open and responsive to the personal constructions and narratives of illness that their patients bring. They must provide a range of action pathways. Such constructs should also allow funders, such as the Health Insurance Commission, to identify the work of psychosocial care and its value. They should provide a common language, or at least, a bridge to other health care disciplines working in the psychosocial area.

In the thesis, I identified the following domains to provide a theoretical base for the evidence for chronic illness care in general practice:

- analysis of the meta-constructs of social support;
- trajectories (and their narratives) of the lived experience chronic illness; and
- general practice processes of ‘enablement’ with appropriate use of consultation time.

This psychosocial evidence needs to be integrated with physiological and disease-based evidence at one polarity and evidence about social and health systems responsiveness.
Implementing biopsychosocial care using support principles

Chronic illness care must be more than ‘non-specific’ processes in a classification system. The roles and tasks of general practice must be clearly demarcated so that they are visible, can be evaluated and remunerated properly or else they will be ad hoc.

The practitioner

In order to provide appropriate chronic illness care, general practitioners need to implement biopsychosocial models of illness and appropriate action frameworks that counter-balance specialist, acute care and disease management models. This entails education, support and feed-back about implementation. Appropriate educational strategies for undergraduate, vocational training, post-graduate training and continuing medical education (CME) are required. During the writing of my thesis, I instigated and provided considerable input into the section on chronic illness and disease in the Royal Australian College of General Practitioners (RACGP) Core Curriculum for vocational training for general practice (RACGP 1997). I have developed a chronic disease review as a CME activity to provide feedback about knowledge, attitudes and practice in chronic illness care. I was a member of the committee that oversaw training for the ACT Co-ordinated Care Trial.
Assess
• Diagnose physical, psychosocial, practical needs and problems

Provide
• Structural support - personal and practice continuity, access
• Information/advice on drugs, treatment, lifestyle
• Emotional reassurance and psychosocial counselling
• Appraisal and practical support
• Possible social companionship

Mobilise
• Refer for physical, psychosocial, practical support
• Coordinate and integrate appropriate sources, facilitate structure of support

The consultation
Because supportive or non-categorical care does not have a nosological classification system nor the process of disease and diagnosis, I argue that an alternative classification system for the chronic illness care and consultation processes and outcomes are required. Dimensions of the consultation can thus be: the patient narrative; disease management; the interpersonal doctor-patient relationship; the support functions provided by the general practice; the enablement that is the outcome of supportive care and the structural, financial and organisational aspect that are reflected in consultation duration. Figure 13.2 outlines a model of chronic illness consultations.

The structure of the practice in relationship to the health system
The practice is the industrial and organisational unit of general practice work. Access to the practice for most patients is through reception staff, who need training and facilitation about responding to the needs of people with chronic disease and illness. The practice provides an important component of the structure of care and people’s support networks. Therefore, the organisation of the practice, its staff, the records and registration, need to incorporate support principles in their design and function. The practice provides an important contribution to care continuity, liaison between the general practice and other providers, a vehicle for care co-ordination that can monitor the patient with a high level of need outside of consultations. Box 13.2 describes the extension of biomedical care into the traditional biopsychosocial model of care that general practitioners typically espouse, but may not necessarily enact. However, the Australian coordinated care trials have also tested a further extension of the role of the general practice into case management involving the purchase of services, overseeing their implementation and monitoring their outcomes. While the trials have not yet reported their formative or summative evaluations, anecdotally, it is this extended role that is providing the most difficulty for general practitioners, being very removed from traditional clinical practice (Ashwell 1998).
The health care system

System—structural, team and network dimensions

Trajectories through stages of illness take people through different parts of the health care system including hospital, day care, rehabilitation, and different types of therapy. Such trajectories have a major impact upon the body, the mind and often people’s social circumstances. Therefore, in order to minimise the potential adverse impact of such trajectories, there is a need for biopsychosocial care planning, care co-ordination, case management and integrated care delivery. In Australia, major barriers to such integrated care are the different funding mechanisms for different parts of the health and social care systems. Co-ordinated care trials and the Repatriation Comprehensive Care Scheme with Annual Health Care Plans are attempting to overcome these structural and funding barriers with the general practice as Care Coordinator. However, if general practitioners and the practice are to play a central role, there is a need for training in broad-based assessment, teamwork and care planning and monitoring to accomplish what is a major paradigm shift for both the general practice and other health care providers. Although many general practitioners may not choose to extend their role to purchasing and direct case management, this thesis strongly demonstrates the need to implement biopsychosocial care for people attending general practice. This entails, at a minimum, that general practitioners should understand biopsychosocial frameworks with access to the growing evidence about the value of comprehensive integrated care on better health outcomes and how to assess and implement care.

Conclusion

In conclusion, I have demonstrated that the needs of people are not being well met in the current system of Australian general practice. The theoretical basis for chronic illness care is poorly developed. At best, responses to chronic illness by general practitioners are an addition to disease management if there is sufficient time, rather than being central to the care process. There are many factors influencing why this is so, but my analysis indicates that the fundamental problem is the lack of a strong conceptual model and an evidence base for the discipline of general practice in chronic illness care. This thesis has developed such a model, that requires further development and operationalisation. Such a model should shape the structure of the health system and the system of general practice organisation and remuneration, as well as education and training. I am actively working to implement a social support based chronic illness model as described briefly in Appendix 4.
Figure 13.2 A model of chronic disease and illness care in general practice consultations

Disease management, Health promotion, Social support

Longer consultations

Patient narratives of disease and treatment, illness and life

Enablement

Treatment adherence, Self-management, Coping, Healing,

Better disease control and quality of life
References


AHMAC. 1993 *Australian Health Ministers Advisory Council Sunshine Statement*, Department of Health And Family Services, Canberra.


Andersen, R. 1968. *A Behavioural Model of Families Use of Health Services* Chicago: Centre for Health Administration Studies, University of Chicago.


Ashwell, S. 1998. Difficulties in extending the role of GPs to purchasing and case management in coordinated care trials ACT Coordinated Care GP Liaison Officer (*personal communication*).


202


Eisenberg, L. 1986. Is there too much science in medicine or not enough? Proceeding from International


Fox, R. 1996. The contribution of Talcott Parsons for contemporary medical sociology. *SocHealth (Department of Humanities and Social Sciences La Trobe University/Albury-Wodonga)* 4:1–8.


STruss, A., Glaser, B. 1975. Chronic Illness and the Quality of Life USA: The CV Moseby Company

214
Sullivan, M. 1993. Mental health in chronic disease. In; Proceedings from the Conference on
The Management of Chronic Disease in an Aging Society. Society for Public health and
Science and University of Amsterdam, Academic Medical Centre, Amsterdam,
Netherlands.

Syme, S. 1989. Control and health: a personal perspective. In Stress, Personal Control and

Thoits, P. 1995. Stress, coping and social support processes: Where are we? What next?

Keynes: The Open University.

Bloomington and Indianapolis: Indiana University Press.

caregivers of cancer patients, In; Proceedings from the Conference on The Management
of Chronic Disease in an Aging Society. Society for Public health and Science and
University of Amsterdam, Academic Medical Centre, Amsterdam, Netherlands.

Harmondsworth, Middlesex, UK: Penguin.

Tavistock Publications.


Sage Publications.

Verbrugge, L. M. 1984. Longer life but worsening health? Trends in health and mortality of
middle-aged and older persons. Milbank Memorial Fund Quarterly Health and Soc 62:475-519


Waitzkin, H., Britt, T. and Williams, C. 1994. Narratives of aging and social problems in


Ware, J. 1994. How to score the SF–36. In SF-36 health Survey manual and interpretation
guide, (ed.) Ware, J et al. Boston, MA: The Health Institute, New England Medical Centre.


Appendix 1

Survey instruments - The Australian Morbidity and Treatment Survey

1. The Australian Morbidity and Treatment Survey Practitioner profile questionnaire

2. The Australian Morbidity and Treatment Survey Encounter recording form
Appendix 1: Practitioner profile questionnaire

Please circle the number corresponding to your answer or write your answer in the space, as appropriate.

<table>
<thead>
<tr>
<th>Personal Information</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sex</td>
<td>Female</td>
<td>1</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>2. Age</td>
<td>&lt;35 yrs</td>
<td>1</td>
</tr>
<tr>
<td>35-54 yrs</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>55+ yrs</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practice Details</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3. How long have you been in general practice?</td>
<td>&lt;2 yrs</td>
<td>1</td>
</tr>
<tr>
<td>2-6 yrs</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>6-10 yrs</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>&gt;10 yrs</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. How many other doctors practise with you? (include partners, associates and assistants) [0 = solo]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Approximately what percentage of your patients in this practice have English as a second language?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0%</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1-24%</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>25-49%</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>50-74%</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>75-100%</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Estimate the percentage of consultations you conduct in languages other than English</td>
<td>Chinese</td>
<td>.01</td>
</tr>
<tr>
<td>Italian</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>Greek</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>French</td>
<td>.04</td>
<td></td>
</tr>
<tr>
<td>Yugoslavian</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td>German</td>
<td>.06</td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td>Which language(s)?</td>
<td>Spanish</td>
<td>.08</td>
</tr>
<tr>
<td>Arabic/Lebanese</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>Hindi</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td>Vietnamese</td>
<td>.11</td>
<td></td>
</tr>
<tr>
<td>Turkish</td>
<td>.12</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>.13</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational Details and Professional Association Membership</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Place of graduation</td>
<td>Australia</td>
<td>1</td>
</tr>
<tr>
<td>Asia</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>America</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Africa</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Pacific</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>8. Which medical postgraduate qualification(s) do you have? (multiple response allowed)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Member or Fellow of RACGP</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>PMP (CST)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Other — Australia</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Other — Overseas</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>(e.g. Dip Obst., FRACS)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>9. To which professional association(s) do you belong? (multiple response allowed)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>College of General Practitioners</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Australian Medical Association</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Private Doctors of Australia</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Doctors Reform Society</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

Column NOS

Column NOS

Column NOS
### Appendix 2: Encounter recording form

**THE PATIENT**

<table>
<thead>
<tr>
<th>SEX (circle)</th>
<th>AGE: (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M / F</td>
<td>1 &lt; yr = 00</td>
</tr>
<tr>
<td></td>
<td>&gt; 99 yr = 99</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient NEW to practice</th>
<th>Seen before in practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**THE PROBLEMS AND THEIR MANAGEMENT**

1. DIAGNOSIS/Problem:

   * STATUS this problem (circle) NEW OLD

   TREATMENT/SCRIPTS for this problem: (up to 4)

2. DIAGNOSIS/Problem:

   * STATUS this problem (circle) NEW OLD

   TREATMENT/SCRIPTS for this problem: (up to 4)

3. DIAGNOSIS/Problem:

   * STATUS this problem (circle) NEW OLD

   TREATMENT/SCRIPTS for this problem: (up to 4)

4. DIAGNOSIS/Problem:

   * STATUS this problem (circle) NEW OLD

   TREATMENT/SCRIPTS for this problem: (up to 4)

**REFERRAL, TESTS, INVESTIGATIONS ordered/undertaken:**

**PATIENT:**

<table>
<thead>
<tr>
<th>Pathology:</th>
<th>X-RAY</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>Plain</td>
<td>E.C.G.</td>
</tr>
<tr>
<td>Urine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Culture</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pap smear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**ADMISSIONS**

<table>
<thead>
<tr>
<th>New referrals to specialists &amp; health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
</tbody>
</table>

**FOLLOW-UP:** Has this patient been asked to return within the next three months for any of these problems? **YES** / **NO**
Appendix 2

"The management of chronic conditions in general practice".

Study instruments and protocols

1. GP information accompanying the invitation to participate in the study

2. Qualitative Study ‘Experiences of disease, illness and treatment’
   protocol and consent forms

3. Patient survey protocol and instrument incorporating a 6 item subset of
   the SF-36 measure (previously known as SF-20)

4. ‘Experiences of disease, illness and treatment’ - Patient interview
   prompt sheets

5. ‘Experiences of disease, illness and treatment’ - GP interview prompt
   sheets
THE MANAGEMENT OF CHRONIC CONDITIONS IN GENERAL PRACTICE

A Study of Patient and Doctor Experiences of the Management of Chronic Diseases in General Practice in Canberra, rural NSW and Melbourne.

An analysis of questionnaire, interview and consultation data.

The Study
Chronic disease and illness care are an important component of the workload of general practice that may not be well understood. This is a study of the management of everyday chronic disease in general practice. It is conducted by a general practitioner under the auspices of the National Centre for Epidemiology and Population Health at the Australian National University. The study will consist of a patient survey, audiotaping patient consultations and interviews with participating GP and patients. It seeks to explore a range of important questions derived through focus groups with GP and patients.

1. What are the experiences of patients and doctors in chronic disease care in the general practice setting?

2. How can types of patient illness experience and doctors' management of patients with chronic disease be defined?

3. What are the patient and doctor factors which make for a better illness experience/good patient management?

4. What are the factors which contribute to unsatisfactory experiences and outcomes?

5. Which strategies and initiatives are effective in monitoring, evaluating and enhancing chronic disease care?

Feedback
Each participating doctor will get a report, and visit or telephone call, if requested, on the results of the study as a whole and of their particular section on the completion of the study in July 1994. However, at any point in the study, Carmel Martin will give preliminary feedback, if requested. Telephone 06 2492837.

Chief Investigator
Carmel M Martin, MB BS, MRCGP(UK), MSc, FAFPHM
Visiting Fellow (NCEPH) and General Practitioner Australian National University, Canberra

Co-investigators
Professor R Douglas MD, FRACGP, FRACP, Director, NCEPH, Australian Nat University
Dr Jeanne Daly, Phd BSc., MSc., Sr Res Fellow, Dept of Sociology, La Trobe, Melbourne
EXPERIENCES OF DISEASE, ILLNESS and TREATMENT

Chronic Conditions

Persons suffering from Chronic Conditions are defined, for the purpose of this study, as those having:-

1. One or more systemic *medical* conditions present for greater than 12 months *with no primary psychiatric pathology* *(see footnote 1)* (Please exclude patients who are in the terminal phase of illness).

2. Prescriptions for two or more medications for longer than 12 months

3. Referrals to two or more specialists over the past 12 months

4. Good command of English and the ability to articulate *(see footnote 2)*

---

1 For example, one medical condition might be diabetes, another condition, hypertension, and another peripheral vascular disease. Menopause is not a medical condition for the purposes of this study, however a chronic gynaecological problem would be suitable.

Patients with a primary psychiatric/psychological problems are not considered suitable because of the complexity in determining which factors affect their experiences, however if, in your opinion, such a problem is secondary to the condition, then the patient should not be excluded. For example, secondary depression to chronic pain.

2 The rationale for this is that, if the experiences of this type of person are problematic, then those of non-English speaking background people are likely to be worse.
Appendix 2.2 Qualitative Study Protocol and Consent Forms

Guidelines for Interviewers

1. **Explanation of Research Aims and conditions**

   Please invite chronic disease patient to attend for interview by telephone. Send in advance of the interview the self-explanatory covering letter, three consent forms, the patient questionnaire to be completed prior to the interview, also send the main questionnaire for patient to peruse but not complete.

   *No names are to be recorded.*

   All the information relating to individuals will remain confidential to the study. When results are available you will be sent a copy to comment on if you wish to.

2. **Consent**

   Please ask the patient to sign the 3 consent forms with a witness. One copy is for the patient, one for your notes and one for the study files.

3. **Open-ended Questions**

   Allow patients as much freedom to express themselves in their own words as possible.

   Encourage patient flow.

4. **Audio-Taping**

   Position the microphone closer to the patient, preferably not on table near the interviewer's papers. Keep all other noises, such as shuffling of papers, etc. to a minimum. Please check quality of recording before the interview.

5. **Post Interview**

   After interview please indicate **any thoughts, feelings, difficulties generated by the interview**. Also any impressions on how the patient felt. Did you feel that this interview was useful for you and in what way.

   See Doctor Questionnaire at the end of Patient Questionnaire. Each patient will be followed up by a researcher to assess the impact of the interview.
THE MANAGEMENT OF CHRONIC CONDITIONS IN GENERAL PRACTICE

Chronic Conditions

Persons suffering from Chronic Conditions are defined, for the purpose of this survey to be recruited by the research assistant, as indicated by the GP to be those on the appointment sheet today having:-

1. One or more systemic medical conditions present for greater than 12 months with no primary psychiatric pathology *(see footnote 1)* (Please exclude patients who are in the terminal phase of illness).

   and

2. Prescriptions for one or more systemic medications for longer than 12 months (prescription for oral contraception and hormone replacement therapy to be excluded)

   and

3. Good command of English and the ability to read and articulate

---

1 For example, one medical condition might be diabetes, another condition, hypertension, and another peripheral vascular disease. Menopause is not a medical condition for the purposes of this study, however a chronic gynaecological problem would be suitable.

Patients with a primary psychiatric/psychological problems are not considered suitable because of the complexity in determining which factors affect their experiences, however if, in your opinion, such a problem is secondary to the condition, then the patient should not be excluded. For example, secondary depression to chronic pain.

2 The rationale for this is that, if the experiences of this type of person are problematic, then those of non-English speaking background people are likely to be worse.
QUESTIONNAIRE
FOR
PATIENTS
ON
LONG TERM*
REPEAT PRESCRIPTIONS

THIS IS AN ANONYMOUS QUESTIONNAIRE
PLEASE COMPLETE
AND RETURN IT IN THE ENVELOPE
PROVIDED

Prepared by: Dr Carmel Martin
National Centre for Epidemiology and Population Health
Australian National University
06 -249 0715
Dear Study Participant,

This study aims to help GPs and others involved in the care and provision of treatment for people who have medical conditions that require long term medication and thus repeat prescriptions from their GP.

The study is confidential. Information relating to an individual will not be revealed. An individual could not be identified by anyone outside the research team.

Your GP supports the study and has allowed the study to take place in his or her practice.

If you require assistance with the questionnaire, a member of the study team is in the practice today to help you with any difficulties.

Dr Carmel Martin,
General Practitioner and Researcher
National Centre for Epidemiology and Population Health
Tel - 06 249 3598
Q1. a. What is your date of birth?

b. Please indicate whether you are: *(Please tick)*
   Female [ ] or Male [ ]

c. How long have you lived in your present district
   (in contact with the same local people, shops and other services)?

d. Which ethnic group do you feel you belong to?

e. What is your marital status? *(please tick)*

   Single [ ] Married [ ] De facto [ ]
   Widowed [ ] Separated [ ] Divorced [ ]
   Other [ ] Describe

f. What are your usual living arrangements? *(tick one box only)*

   Live alone [ ]
   Live with spouse/partner only [ ]
   Live with spouse/partner and other family [ ]
   Live with parents only [ ]
   Live with parents and other family [ ]
   Live with brother(s)/sister(s) [ ]
   Live with others (please state - eg friend, cousin) [ ]

g. How much education have you had?

   Still at school? [ ]
   Less than three full years at Secondary School? [ ]
   Three or more years at Secondary School? [ ]
   Certified training course or apprenticeship? [ ]
   University or Training College? [ ]
Appendix 2.3

h. **What is your job or occupation?** *(Please describe you occupation fully, e.g. dental nurse, auto electrician, etc. If retired or unemployed, please say so and give your previous occupation, e.g. retired construction foreman)*

i. **Which of the following best describes your main state of employment** *(tick most appropriate)*

- Full-time paid? [ ]
- Part-time paid? [ ]
- Voluntary work (No pay and excluding home duties)? [ ]
- Looking after home and family full time? [ ]
- Looking for work (including unemployment benefit)? [ ]
- On Benefit or Superannuation and not working (other than unemployment benefit)? [ ]
- School or other student? [ ]

Q2 a. **How many prescribed medications are you currently taking?**

How many current prescribed medications have you taken for more than 12 months? *(that is - had a repeat prescription for SINCE BEFORE EASTER 1992)*?

b. **Please describe all your medical conditions and the approximate year each one started - only include those which have been diagnosed by a doctor.**

*(For example, diabetes, 1976)*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Year Started</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2.3

Q3. About your GP care, in the past 12 months SINCE EASTER 1992, to the best of your recollection, give the following details:

a. Do you have a **regular GP**?  
   Yes [ ]  
   No [ ]

b. What is the name of your regular GP
   ____________________________

c. How long have you been with this doctor?
   ____________________________

d. Why did you change to this GP from previous GP?  (Tick one only main reason)
   Dissatisfied with previous GP [ ]
   Previous G.P left/moved/died [ ]
   Dissatisfied with the Practice [ ]
   Costs of seeing G.P [ ]
   GP not always available when needed [ ]
   You moved [ ]
   Found it too difficult to get to practice [ ]
   Other (please describe) [ ]

e. How many GPs have you seen in the past 12 months SINCE EASTER 1992?  (Please place a tick by the appropriate number)
   1 [ ]
   2 [ ]
   3 [ ]
   4+ [ ]

f. Did they all belong to the same practice?  
   Yes [ ]  
   No [ ]

   If No, how many practices have you attended in that period?______

g. How many medical specialists have you seen in the last 12 months SINCE EASTER 1992?

   List the type of specialist and the number of visits to each type of specialist
   
   Specialist type:  Number of visits:
   ____________________________
   ____________________________
   ____________________________
   ____________________________
Appendix 2.3

h. List the number of times you have consulted the following health professionals in the past 12 months SINCE EASTER 1992.

   _______ Physiotherapist _______ Occupational Therapist _______ Community Health Nurse
   _______ Social Worker _______ Dietician _______ Pharmacist
   _______ Psychologist _______ Speech Pathologist _______ Other
   _______ Nurse Practitioner

i. Number of visits to Casualty which did NOT result in admission in the past 12 months SINCE EASTER 1992? ___________

j. Have you been admitted to a hospital in the past 12 months SINCE EASTER 1992?
   Yes [   ] No [   ]
   If Yes, list no of admissions: ___________

k. Have you had any operations or procedures in the past 12 months since Easter 1992?
   For example: catheter removal, hysterectomy, endoscopy (insert tube to examine insides)
   Yes [   ] No [   ] If Yes, please list

l. List the number of times you have consulted the following alternative health practitioners in the past 12 months SINCE EASTER 1992.

   _______ Herbalist _______ Acupuncture _______ Chiropractor
   _______ Naturopath _______ Other (list)

m. Do you belong to a self-help group? (e.g., multiple sclerosis society).
   Yes [   ] No [   ] If Yes, please list.

   ________________________________________________________________
   ________________________________________________________________

n. Do you belong to any other type of groups, e.g. church group, bridge club, hobby society? Yes [   ] No [   ] If Yes, please list:

   ________________________________________________________________
   ________________________________________________________________


Appendix 2.3

The following are questions related to your general health.

Q4

a. In general, would you say your health is: (please tick)

1. Excellent [  ]
2. Very Good [  ]
3. Good [  ]
4. Fair [  ]
5. Poor [  ]

b. How much bodily pain have you had in the past four weeks?

1. None [  ]
2. Very mild [  ]
3. Mild [  ]
4. Moderate [  ]
5. Severe [  ]
6. Very Severe [  ]

c. For how long (if at all) has your health limited you in each of the following activities? (Tick one box on each line)

<table>
<thead>
<tr>
<th>Limited for more than 3 months</th>
<th>Limited for 3 months or less</th>
<th>Not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Activities like lifting heavy objects, running or participating in strenuous sports</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. Activities like moving a table, carrying groceries or bowling</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. Walking uphill or climbing a few flights of stairs</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. Bending, lifting or stooping</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. Walking one block</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. Eating, dressing, bathing or using the toilet</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>
Appendix 2.3

d. In the past 12 months has your health kept you from working at a job, doing work around the house or going to school?

1. Yes, for more than three months  [ ]
2. Yes, for three months or less  [ ]
3. No  [ ]

e. Have you been unable to do *certain kinds of work*, housework or schoolwork because of your health in the past 12 months?

1. Yes, for more than three months  [ ]
2. Yes, for three months or less  [ ]
3. No  [ ]

f. For each of the following questions, please tick the box for the answer that comes closest to the way you have been feeling for the past month.

<table>
<thead>
<tr>
<th>A good bit of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
</table>

(Tick one box on each line)

i. Limited your social activities (like visiting friends, or close relatives)?

[ ] [ ] [ ] [ ] [ ] [ ] [ ]

ii. How much of the time, during the past month, have you been a very nervous person?

[ ] [ ] [ ] [ ] [ ] [ ] [ ]

iii. During the past month, how much of the time have you felt calm and peaceful?

[ ] [ ] [ ] [ ] [ ] [ ] [ ]
f. cont.
For each of the following questions, please tick the box for the answer that comes closest to the way you have been feeling for the past month.

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A good bit of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>iv</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

   How much of the time, during the past month, have you felt down in the dumps and miserable in yourself?

v       During the past month, how much of the time have you been a happy person?

   [ ] [ ] [ ] [ ] [ ] [ ]

vi.      How often, during the past month, have you felt so down in the dumps that nothing cheers you up?

   [ ] [ ] [ ] [ ] [ ] [ ]

g. Please tick the box that best describes whether each of the following statements is true or false for you.
   *(Tick one box on each line)*

<table>
<thead>
<tr>
<th></th>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Not Sure</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am somewhat ill</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. I am as healthy as anybody I know</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3. My health is excellent</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. I have been feeling bad lately</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>
Appendix 2.3

Q5. Place a number along the line that best describes what you think.

a. My life has not been affected by my illness
   0 | 2 | 4 | 6 | 8 | 10
   (My life has been affected by my illness)

b. My treatments have improved my quality of life
   0 | 2 | 4 | 6 | 8 | 10
   (My treatments adversely affected my quality of life)

c. My illness has not changed the way I feel about myself
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has changed the way I feel about myself)

d. My illness has not changed my life plans
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has changed my life plans)

e. My illness has not affected my family
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has affected my family)

f. My illness has not affected my work
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has affected my work)

g. My illness has not affected my finances
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has affected my finances)

h. My illness has not made me a burden to others
   0 | 2 | 4 | 6 | 8 | 10
   (My illness has made me a burden to others)

i. My illness has no control over my life
   0 | 2 | 4 | 6 | 8 | 10
   (My illness controls my life)

j. I have no control over my life
   0 | 2 | 4 | 6 | 8 | 10
   (I have control over my life)

k. The people who treat me don’t control my lifestyle
   0 | 2 | 4 | 6 | 8 | 10
   (The people who treat me control my lifestyle)
Appendix 2.3

Q6. We want to know what you value in a GP
Place a number from 0-5 in the box to tell us how important each item is in your care.

Key

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Very</td>
</tr>
<tr>
<td>4</td>
<td>Somewhat</td>
</tr>
<tr>
<td>3</td>
<td>A little</td>
</tr>
<tr>
<td>2</td>
<td>Hardly</td>
</tr>
<tr>
<td>1</td>
<td>None at all</td>
</tr>
<tr>
<td>0</td>
<td>Don't know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Qualities of General Practitioner</th>
<th>Important to My Care (1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medically and technically skilled</td>
<td></td>
</tr>
<tr>
<td>Feel comfortable in presence of GP</td>
<td></td>
</tr>
<tr>
<td>Reasons logically</td>
<td></td>
</tr>
<tr>
<td>Induces enthusiasm/bucks me up</td>
<td></td>
</tr>
<tr>
<td>A good listener</td>
<td></td>
</tr>
<tr>
<td>Coordinated my care</td>
<td></td>
</tr>
<tr>
<td>A friend I could turn to</td>
<td></td>
</tr>
<tr>
<td>Good relationship with specialist</td>
<td></td>
</tr>
<tr>
<td>Team member who managed my care</td>
<td></td>
</tr>
<tr>
<td>Available when needed</td>
<td></td>
</tr>
<tr>
<td>Responsive office staff</td>
<td></td>
</tr>
<tr>
<td>Willing to be my main doctor</td>
<td></td>
</tr>
<tr>
<td>Good Communicator</td>
<td></td>
</tr>
</tbody>
</table>
Q7. Please place a number on the line to tell us about your experience of care under your General Practitioner

<p>| | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>It is important to have the same GP</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(It is not important to have the same GP)</td>
</tr>
<tr>
<td>b.</td>
<td>It is important for my GP to work closely with my specialist</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(It is not important for my GP to work closely with my specialist)</td>
</tr>
<tr>
<td>c.</td>
<td>My GP works hard to make sure I get all the help I need</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(I do not get all the help I need from my GP)</td>
</tr>
<tr>
<td>d.</td>
<td>My GP coordinates my care</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(My GP does not coordinate my care)</td>
</tr>
<tr>
<td>e.</td>
<td>My GP listens to me</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(My GP does not listen to me)</td>
</tr>
<tr>
<td>e.</td>
<td>My GP gives me comfort and support</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(My GP does not give me comfort and support)</td>
</tr>
<tr>
<td>f.</td>
<td>My GP is honest regarding my health about</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(My GP does not tell me everything I should know my health)</td>
</tr>
<tr>
<td>f.</td>
<td>In the past three months I have followed exactly all of my GP’s instructions</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>(In the past three months I have not followed any of my GP’s instructions)</td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR TIME AND EFFORT
EXPERIENCES OF DISEASE, ILLNESS AND TREATMENT

AUDIO-TAPED INTERVIEW

Q1.
Tell me about your medical conditions

Tell me about your life before and since you have had these conditions

Prompts:

• Life stage? e.g. young couple with children and mortgage/retired with no major responsibilities.
• How has your life been affected?
• How do you feel in yourself? your physical and mental symptoms?
• Do you see yourself as ill? having chronic disease?
• Able to live a normal life? what restrictions? are you bothered by these restrictions?
• Effect on how you feel about yourself? your life plans?
• Effect on your family? work? finances?
• Do you feel a burden to others? What is the effect of disclosing any pain or suffering that you might experience?
• Do you have control over your life or is your life controlled by your disease symptoms, medications and/or by those who are treating you?
• Are you in contact with others with similar conditions to yourself?
• What experience have you or your family close friends had with respect to these conditions?

Q2.
Tell me about your experiences of your GP and other medical care since you have had these conditions

• Since you have had these conditions, how have GPs been involved in your care? what has been helpful about your contact with GPs? Any problems with GPs?
• How have specialists and other health care workers been most helpful to you?
• What qualities do you look for in a GP? medical and technical skills, empathy, supportive, friendliness
• What do you outcomes do you expect from the care by your GP
• How satisfied are you with the amount of time you can access in consultations?

Q3
Please describe your worst experiences since you have had medical conditions.

• your personal experiences, pain, care, medication etc
• Is there any way, things could have been made easier for you by your GP? by specialists? by hospitals?
What are your best experiences of care since you have had medical conditions?

- personal, family, social?
- what were the elements of the best care you received? from whom?

Q4

How important have General Practitioners been in the co-ordination or organization of your care once you have been referred to specialists or hospital or community services.

Prompts
- duplication /fragmentation of services
- co-ordination or organization of your care once you have been referred to specialists or hospital or community services.
- costs?

Q5

How well have your needs for services, treatment, and medications been addressed?

- problem with access to appointments e.g. waiting times, treatments e.g. physio, benefits, medications e.g. too costly

Q6

How do you see that your GP could be more helpful. How important is communication with your GP, your specialist and others involved in your care?

Prompt
- Do feel that your GP, your specialist and others involved in your care understand about your medication, your conditions, your progress and the effect of these on your life?
- Would you like to have more explanation about your conditions and treatment.

Q7

Has continuity of care (having the same GP) been important to you or not? Discuss

Prompts:
- How often have you changed or consistently attended one GP.
- Why change/not change?
- Benefits/disadvantages of continuity
- Do you value the relationship with your doctor? in what way? is there anything special about the relationship? what do you look for in such a relationship?
Appendix 2.4

Q8.
How important has support given to you by your GP, your specialists and others involved in your care been important for you.

How could General Practitioners be more helpful in this regard?

Prompts:
- Emotional, psychological support to patient and family.
- Support with practical help in terms of benefits, aids, appliances etc
- Informational support

Q9.
In the past week (if it is a typical week) describe social contacts

- no of clubs, organisations, meetings self-help groups etc attended
- no of contacts with family or close friends
- no of contacts with service providers-meals on wheels, home help, • community nursing, doctor, receptionists
- no of significant contacts with storekeepers, hairdressers etc

Any problems with social support?

Q10.
Since you have had any of the medical conditions, when, if at all, have you felt vulnerable (open to forces beyond your control)

- What makes you vulnerable? coping strategies Who was most help at these times -family, professionals friends? why? what was helpful
- phase of illness, time/place of treatment, or personal situation
- physically/psychologically/socially/finances work

Since you have had any of the medical conditions, when, if at all, have you felt futile (lack of hope, belief in your treatment, medical attendants, health professionals, at the mercy of your condition etc)

- Do you often get anxious and depressed/ effect on self-esteem?
- Who was most help at these times -family, professionals friends? why? what was helpful
- phase of illness, time/place of treatment, or personal situation
- physically/psychologically/socially/finances work

Q10.
What factors influence whether you take or not take a medication that is prescribed?

De-briefing:
Affirm the positive aspects of the patients coping strengths and ask about the need for follow-up to discuss issues raised in the interview

General Practice Evaluation Program
National Centre for Epidemiology and Population Health
Australian National University
Experiences of disease, illness and treatment

GP Interview Prompt Sheet

About you

- Name
- Practice location
- Practice type
- Date of Qualification
- Postgraduate Diplomas or other qualifications
- No of years in General practice/this practice
- VR/NonVR
- Teaching commitments
- Involvement with RACGP, AMA etc

About you medical care

- How did you come to study medicine?
- How did you come to do general practice? / this practice
- Open ended statement about your philosophy of medical care
- What type of patient/ problem do you particularly enjoy. Why?
- What type do you particularly find difficult/ distressing/ boring. Why?
Appendix 2.5

Your views on chronic disease and illness

Experience of chronic disease, chronic disease patients

The role of the GP and general practice

Issues/Problems in Chronic Disease management for doctors - prevention, management

Views on illness when self-efficacy breaks down

The role of the GP and general practice - personal and psychosocial care

Pain of practice

Overall job satisfaction

What is a good consultation?
With different types of patients?

GOOD-------------------------------------BAD

• control over disease/illness/, discussion,

• staying in the technical,

• doing something,

• dealing with the social,

• legitimate unjustifiable

• false positives and negatives-pick-up rate, low disease prevalence

• “hear the pain”

• buying time,

• classification of seriousness,
Audio-taped consultations study
Patient No:
Name:
DOB:
Address:

Q1. How long have you known this patient?

Q2. How many times have you seen this patient in the past year?

Q3. What do you feel are the main problems faced by this patient:

What are your particular concerns with this patient?

Q4. a Please describe -
- their medical condition
- their medication
- other professional input
- lifestyle and family support

Q4.b Do you feel the patient is mildly / moderately / severely disabled by their condition(s)?

Q5. What is the your interpretation of the patient's experience of illness. Please describe.

In retrospect, would you have managed your patient differently?

Will this have any impact on your management of the patient in future? If so, in what way?

Q6. What is your interpretation of the patient’s best and worst experiences of health care

In retrospect, would you have managed your patient differently?

Will this have any impact on your management of the patient in future? If so, in what way?

Q7. What is your interpretation of the patient's experience of General Practice management, support, communication, and co-ordination of care

Q8 What is your interpretation of the patient's experience of specialist and other health professional management and care.

Please describe briefly any thoughts, feelings, difficulties, ideas generated
Appendix 3

Supplementary evidence from

“The management of chronic conditions in general practice”.

WHAT DO LONGER CONSULTATIONS PROVIDE?

PRECONDITIONS FOR PSYCHOSOCIAL SUPPORT IN GENERAL PRACTICE CONSULTATIONS

A qualitative study of Consultation Length and Biopsychosocial Care

Final Report

General Practice Evaluation Program

Chief Investigator: Dr Carmel Martin, Co-investigator: Dr Dorothy Broom
Research Assistant: Cathy Banwell
Project Information

1. Grant Type and GPEP Number

GPEP Seeding Grant No 498

2. Project Title

Preconditions for psychosocial support in general practice consultations

3. Date of project commencement

May 1997

4. Date of project completion

October 1997

5. Names of Chief Investigator and co-investigator(s)

Chief Investigator: Dr Carmel Martin

Co-investigator: Dr Dorothy Broom

6. Administering organisation

National Centre for Epidemiology and Population Research
Australian National University
Canberra ACT 0200
7. Executive summary (up to 500 words)

Research indicates that psychosocial support is an important element in the effective management of chronic conditions.

**Aim:** to identify the structural (including GP knowledge and skills, consultation, prior knowledge of the patient) and processual (interaction between patient and practitioner) conditions for general practitioners to supply suitable psychosocial support for their clients with chronic illness.

**Objectives:**
- To identify, on the basis of patient reports, supportive consultations
- To identify, on the basis of patients’ reports, supportive relationships with GPs
- To distinguish the characteristics of consultations identified as supportive from those not so identified
- To begin development of an inventory of skills that GPs might acquire to improve the effectiveness of their support to patients with chronic conditions

This project employed existing data to identify the preconditions that should prevail to assist general practitioners supply suitable psychosocial support to their clients with chronic illnesses. The existing data was collected as part of a larger project on the management of chronic disease in general practice. It consists of transcripts of 106 consultations between 14 GPs and 50 patients who have chronic conditions (GPEP Project Grant 155: The management of Chronic Conditions in General Practice (Martin 1994)).

Fourteen general practitioners (7 female, 7 male) were purposively selected to represent urban, rural and inner-city group and single-handed general practice. They were identified through GP networks as being medical teachers and ‘good’ GPs. Research assistants visited the practice on selected days and audio-taped consultations of up to 5 consecutive attenders of people with ‘complex chronic conditions’ - on long-term medication with multisystem but not primarily psychiatric problems. GPs were then asked to audio-tape 3 additional consecutive consultations with these people. One hundred and six consultations were transcribed and subjected to thematic analysis using the Ethnographic 4.0 computer package (Seidel, Freise, & Leonard, 1995).

Relationships between consultation duration and support processes were explored in these audiotaped consultations. The duration of consultations was: <6 minutes (3 consultations); 6-9 minutes (23 consultations); 10-19 minutes (47 consultations); 20+ minutes (33 consultations). The most frequent themes that appeared in all consultations were: GP information giving, GP review of treatment options, GP review of course and nature of medical condition; GP practical and lifestyle support. Less important themes were related to aspects of patients’ emotional and social lives. The majority of the discourse on all themes was GP rather than patient initiated. Longer consultations had greater patient initiation of dialogue. However, a small proportion of short consultations was initiated by patients around a specific requirement such as prescription renewal.
8. Background and rationale

Considerable research shows that the availability of psychosocial support is an important element in the effective management of chronic conditions. Such long-standing health conditions form an increasing component of the illness burden in developed societies, and a significant element in the use of health and welfare services, including general practice. Social support has been identified as an important component in promoting improved physical and psychosocial health outcomes. Olsen's meta-analysis of 9 major cohort studies found an association between better social networks and lower mortality in middle aged white men (Olsen, 1992). The benefits of social support to chronic conditions are of particular importance. Poorer mental health and social support has been shown to be some of the important factors in predicting outcomes in a UK study of chronic physical-ill health (Goldberg & Huxley, 1992). However, while there has been considerable development in social support theory, there is a lack of tangible understandings of social support applicable to general practice care (Thoits, 1995), (Martin & Nisa, 1996). If GPs are to deliver effective social support, it is important that they are equipped to reflect on their practice and to be aware of the behaviours that patients experience as supportive.

9. Literature Review (indicate scope and method)

A literature review was not proposed as part of this study as a substantial literature review has been conducted already by Dr Carmel Martin, as part of the overall project of which this study is but one small part. The paper resulting from that literature review is appended to this document.

10. Aims and Objectives

Aim: to identify the structural (including GP knowledge and skills, consultation, prior knowledge of the patient) and processual (interaction between patient and practitioner) conditions for general practitioners to supply suitable psychosocial support for their clients with chronic illness.

Objectives:
To identify, on the basis of patient reports, supportive consultations
To identify, on the basis of patients reports, supportive relationships with GPs
To distinguish the characteristics of consultations identified as supportive from those not so identified
To begin development of an inventory of skills that GPs might acquire to improve the effectiveness of their support to patients with chronic conditions
11. Methodology and methodological issues (including theoretical framework, research design, methodological limitations, sampling methods etc)

This project employed existing data to identify the preconditions that should prevail to assist general practitioners supply suitable psychosocial support to their clients with chronic illnesses. The existing data was collected as part of a larger project on the management of chronic disease in general practice. It consists of transcripts of 106 consultations between different GPs and 50 patients who have chronic conditions (GPEP Project Grant 155: The management of Chronic Conditions in General Practice (Martin 1994)).

Fourteen general practitioners (7 female, 7 male) were purposively selected to represent urban, rural and inner-city group and single-handed general practice. They were identified through GP networks as being medical teachers and 'good' GPs. Specifically, three GPs were located in inner-city Melbourne - 1 from a large group practice, 1 from a single-handed practice and 1 from a large community health centre. Nine GPs practiced in Canberra, 1 in a single-handed practice, 2 were in single-handed practices but with assistants and 4 were from community health centres which were closed after the study period. Four GPs were from rural two-GP practices.

Research assistants visited the practice on selected days and audio-taped consultations of up to 5 consecutive attenders of people with 'complex chronic conditions' - on long-term medication with multisystem but not primarily psychiatric problems. GPs were then asked to audio-tape 3 additional consecutive consultations with these people. One hundred and six consultations were transcribed and subjected to thematic analysis using the Ethnographic 4.0 computer package.

GP attenders in the study completed semi-structured interviews. In addition, they completed a detailed social support questionnaire modelled on the multi-dimensional support scale of Winefield (Winefield & Katsikis, 1987). The survey data consist of:

- **Personal Profiles**
  - Diagnostic and non-categorical markers of disease(s)
  - Social support needs and satisfaction
  - Socio-demographic factors

- **Illness Outcomes or Morbidity Burden**
  - Illness impact scale
  - SF-36

- **GP Care Profile**

- **Other Health Care Network**
  - Range and type of health care providers
  - Number of specialist, allied health and other consultations
The components of the study funded by this grant were:

(I) coding of the GP attender’s questionnaires  
(ii) the entry of this data into SPSS  
(iii) initial analysis of this data to produce a description of the GP attenders  
(iv) development of a coding frame for use with the consultation transcripts  
(v) coding consultation transcripts  
(vi) first pass analysis of the coded consultations

12. Analysis

Ethnograph V4.0 was used to assist in the management of the data during the process of analysis. Analysis of consultations consisted of attaching codes to sections of text that could then be retrieved. The codes used were not mutually exclusive and were generally of the type described by Seidel (Seidel, Freise, & Leonard, 1995) as a heuristic device for further examination and comparison.

## Coding Framework

<table>
<thead>
<tr>
<th>Codeword</th>
<th>Code Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONTINUITY</td>
<td>indication of relationship over time between patient and GP</td>
</tr>
<tr>
<td>GP/PAT.NEG</td>
<td>negotiation between GP and patient about management, treatment etc.</td>
</tr>
<tr>
<td>GP/SPEC</td>
<td>examples of the GP acting as a go-between for the patient and specialist, or referring to a specialist, discussing feedback from specialist</td>
</tr>
<tr>
<td>GPAPOL</td>
<td>GP apologises for treatment or other problems in consultation eg keeping patient waiting</td>
</tr>
<tr>
<td>GPPAPPRAIS</td>
<td>GP appraisal of patient’s appearance</td>
</tr>
<tr>
<td>GPPCHANGE</td>
<td>GP changes the topic of conversation abruptly or does not follow up on what patient is saying</td>
</tr>
<tr>
<td>GPEMOT</td>
<td>GP’s enquiries or discussion about patient’s psychological or emotional condition</td>
</tr>
<tr>
<td>GPEMOTPATH</td>
<td>GP expresses empathy or ‘I know how you feel’ types of sentiments</td>
</tr>
<tr>
<td>GPENC</td>
<td>GP’s encouragement (or support) of what the patient is talking about or doing</td>
</tr>
<tr>
<td>GPEXAM</td>
<td>GP conducts examination</td>
</tr>
<tr>
<td>GPEXPERT</td>
<td>display of expert medical knowledge</td>
</tr>
<tr>
<td>GPFAM</td>
<td>signs of GP’s familiarity with patient’s personal life</td>
</tr>
<tr>
<td>GPFRIEND</td>
<td>GP friendship - signs of support or activity outside usual GP/patient relationship</td>
</tr>
<tr>
<td>GPINFO</td>
<td>GP provides information on medical condition, treatment, management etc.</td>
</tr>
<tr>
<td>GPJOKE</td>
<td>GP’s jocular tone or attempts to lighten the consultation</td>
</tr>
<tr>
<td>GPPERSINFO</td>
<td>GP provides personal information about themselves</td>
</tr>
<tr>
<td>GPPRAC</td>
<td>practical activities or advice by the GP</td>
</tr>
</tbody>
</table>
13. Results

Sixty-seven percent (28) of the patients who took part in taped consultations were female and 33% (14) were male. They ranged in age from 21 to 81 years of age. The mean age was 65 years and the median was 69 years. Twenty-nine % were under the age of 60, 22% were in their 60s, 47% in their 70s, and 1 patient (2.4%) was in their 80s. Three patients (7%) were single, 50% were married, and 43% were widowed, separated or divorced. Thirty-three percent were living alone, 45% were living with their spouse and 21% were living with a family member. Sixty-nine percent were on benefits, or superannuation, 10% were employed full or part-time and 14% were looking after a home and family.

In the remainder of this report the thematic content of the consultations is described to provide the reader with a sense of what occurred within these consultations overall. These same themes are then related to the duration of consultation.

THE CONSULTATIONS

Typically in the study consultations, the general practitioner initiated the dialogue by asking the patient how they were going or what they (the GP) could do for them. Patients occasionally responded as if they were asked a “social” question, but usually this was taken by the patients as the cue to introduce the purpose of their visit. It was at this point that the biomedical discourse was introduced into the consultation, with the patient briefly describing a condition or symptoms in response to the GP’s questioning. Generally, the GP led the exchange with the patient responding until the GP concluded by making a diagnosis, and/or suggesting some course of action such as

<table>
<thead>
<tr>
<th>Codeword</th>
<th>Code Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPREASSURE</td>
<td>GP reassures patient about condition</td>
</tr>
<tr>
<td>GPSOC</td>
<td>GP’s questions or discussion about patient’s social circumstances</td>
</tr>
<tr>
<td>GPSYMP</td>
<td>GP expresses sympathy or support for patient’s difficulties</td>
</tr>
<tr>
<td>GREETING</td>
<td>the introduction process</td>
</tr>
<tr>
<td>HEALING</td>
<td>how or why healing works or discussion of healing process</td>
</tr>
<tr>
<td>LANGUAGE</td>
<td>examples of specific GP language such as the use of “we”</td>
</tr>
<tr>
<td>OTHER</td>
<td>interesting data not included elsewhere</td>
</tr>
<tr>
<td>PATCOMP</td>
<td>patient’s complaint of GP treatment or some other aspect of the medical system</td>
</tr>
<tr>
<td>PATILLNESS</td>
<td>patient’s description of their illness, complaint or condition</td>
</tr>
<tr>
<td>PATINIT</td>
<td>where the patient initiates conversation, comment etc.</td>
</tr>
<tr>
<td>PATJOKE</td>
<td>joke or jocular tone by patient</td>
</tr>
<tr>
<td>PATPERSONINF</td>
<td>patient talking about their social and emotional lives.</td>
</tr>
<tr>
<td>PATREQUEST</td>
<td>request by patient for information, prescription etc.</td>
</tr>
<tr>
<td>REVCLIFE</td>
<td>GP’s review of patient’s condition in light of their life</td>
</tr>
<tr>
<td>REVILL</td>
<td>GP’s review of patient’s condition</td>
</tr>
<tr>
<td>REVTEST</td>
<td>GP’s review of need for tests or test results</td>
</tr>
<tr>
<td>REVTREAT</td>
<td>GP’s review of treatment and prescribing regimes</td>
</tr>
<tr>
<td>SOCTALK</td>
<td>Social talk - not related to patient’s condition</td>
</tr>
<tr>
<td>WRAPUP</td>
<td>the finishing process</td>
</tr>
</tbody>
</table>
an examination, further tests or treatment. Because patients had chronic and sometimes multiple conditions that brought them into regular contact with their GP, these consultations frequently also involved discussion about visits to specialists, tests, and monitoring of health indicators such as weight, blood pressure, and blood sugar levels.

Codes were used to flag or index sections of text that were discursive exchanges between doctors and patients. Using this approach the following types of exchanges that were led by doctors appeared most commonly: 1) GP information giving, 2) GP review of treatment options, 3) GP review of the course and nature of medical conditions; 4) GP practical and lifestyle support. An important patient-led theme was their descriptions of their medical conditions. These major themes will be described below.

**Biomedical Themes**

**Theme 1** Much of the discourse by GPs in the consultations was concerned with the provision of information. Generally, it concerned some aspect of the medical condition of the patient, such as the symptoms, the condition, the treatment, test results, or even the medical system itself. Such information was expressed clearly without the use of complex medical terms. GPs in the study rarely used medical jargon unless they were in the company of another doctor. As the following consultation illustrates information provided by doctors frequently had a reassuring quality, portraying a problem as something that was simple because it could be broken down into constituent parts, and then managed or controlled. In this excerpt the doctor mentions that people worry because they lack information and thus subtly reassures the patient that they have no need to be concerned because they have the necessary knowledge to assess the situation realistically.

\[D:\ \text{Oh this can just happen, you know. Yeah the thing is you're going to be prone to it with varicose veins because in varicose veins the blood isn't moving, it's just sitting there. So it can clot.} \]

\[P:\ \text{Yes that's what I'm -} \]

\[D:\ \text{What people get terrified about is they think oh a clot in the leg means you're going to get a clot in the lung and you're going to die. Well that's not true. There are two types of veins in your leg. There is the ones on the surface and the ones deep inside.} \]

\[P:\ \text{Oh I see.} \]

**Theme 2** Another common and important theme involved the review and discussion of treatment. Much of this was dominated by discussion of prescription drugs. As this excerpt exemplifies some patients were taking a range of drugs and GPs as well as the patients themselves were clearly concerned to keep track of drug use and drug effects singly and in concert with other drugs. Discussions revolved around listing the drugs and in what quantities, patients were taking, monitoring and managing the effects, and
setting up workable drug-taking regimes for patients. In this consultation the doctor goes on to advise the patient to eat acidophilus yoghurt while taking antibiotics.

D:  I'll be writing all sorts of strange dates on these. OK. Yeah. Perhaps if we gave you the Rulide last time, I'll give you Tetracycline this time.

P:  OK.

D:  I'll give you Doryx and that so you can take two tonight after your dinner and then after that, just one a night. And I'll put just one repeat on it. Are you needing any of your asthma stuff?

P:  No.

Commonly, towards the end of the consultation as the GP was finishing up they would ask if the patient needed any prescriptions. Sometimes there was discussion about the risks associated with particular drugs and less frequently, negotiation occurred between the GP and patient over some aspect of drug use.

**Theme 3** The third major area was the GP's review of patients' illness or condition in which the GP enquired about the patient's symptoms and thus elicited from the patients, to a lesser or greater extent, the patient's description and sometimes analysis of their condition. The GP's review of the patient's condition and the patient's description will be discussed in more detail in the section on consultation duration.

**Theme 4** An important theme in most consultations concerned the GP offering practical advice to manage a condition. This theme predominantly involved a biomedical discourse but also included talk about aspects of patients' social lives and also the domain of the health care system itself. Such advice might range from suggesting a patient wear a hat when in the sun to prevent sun spots or to buying over the counter treatments from the pharmacist for skin rashes. Some GPs discussed broad social and familial issues with their patients in the management of their conditions as well as taking practical everyday issues into account. Such advice included activities to place reminder notices in obvious sites, to resume hobbies that patients had enjoyed with friends, or to leave the heating on a little longer during winter.

**Lesser Themes related to Clinical Skills**

One such theme that occurred quite frequently in consultations involved discussion about specialists. In many of these discussions, the GP acted as a bridge or a translator between the patient and the specialist by asking the patient if they had seen the relevant specialist recently, reviewing and discussing the results of the specialists visit and explaining complex medical treatment in plain language and occasionally phoning the specialist to check on aspects of the patient's care and management. They also absorbed patients' complaints or dissatisfaction with specialists - usually
with “professional” objectivity but occasionally expressing mild surprise or disquiet at a specialist’s advice to a patient.

Among minor themes within the biomedical focus of most consultations was the time spent discussing medical tests, whether they patient should have them, what were patients’ test results and what they meant. Less talk within the consultations concerned GP’s examination of patients. This may be because these patients are frequently attending their doctors in the management of chronic conditions that have already been examined and diagnosed. In addition, there was rarely much talk associated with a physical examination as it is conducted in silence or with a few comments from GPs about what they are doing, (or seeing, feeling, hearing). Patients sometimes approached doctors with specific requests that were usually in the biomedical sphere (usually for prescriptions).

**Functional Social Support**

A group of themes concerned not the biomedical aspects of the consultation but instead the functions of social support within the consultation. Functions of social support have been identified as emotional instrumental, informational support, appraisal and social companionship (House & Kahn, 1985). Informational support dealt mainly with the biomedical sphere. Those aspects of support outside it concerned doctors’ encouragement of patients, and also their reassurance of, and less frequently, sympathy and empathy with, patients. Encouragement and positive statements from GPs were most likely to involve monitoring of chronic conditions such as “your haemoglobin’s terrific”, “your blood sugar’s great”, “that’s good you’ve lost weight” etc thus fulfilling a role in the control and management of the condition. Such positive reinforcement however, may reinforce the link between these conditions and the behaviour of patients. While many of these conditions are affected by the patient’s behaviour, they are not entirely under the patient’s control. However, as the following excerpt illustrated patients and GPs conflated good health or good tests results (blood pressure, sugar levels, etc) with good behaviour.

\[
D: \text{ Well we will just check your blood pressure before you go} \\
150 \text{ on 90 is alright.}
\]

\[
P: \text{ That will do it.}
\]

\[
D: \text{ Okay there you just say a brief consult with the lady outside} \\
\text{ and you are right.}
\]

\[
P: \text{ I must be behaving myself mustn’t I.}
\]

\[
D: \text{ You are.}
\]
When things did not go so well the doctors did not make negative statements. Occasionally, they might say something like “Oh dear, your blood pressure has risen”. However, because good results and good behaviour were so closely linked it is likely that patients would feel a sense of personal failure when their results were not positive.

Other forms of encouragement generally affirmed patients’ actions, decisions, choices. Often when patients talked about taking a course of action they did not overtly ask the doctor but to be looking for the GP’s approval. Such approval was sought for actions directly concerned with conditions, (such as drinking more water, changing a diet etc.) but patients also asked for advice within the social sphere such as deciding whether to go on a long trip as these 2 excerpts illustrate. In the first one the patient has told the doctor that she thinks she has successfully managed a urinary tract infection by drinking lots of water.

P: yes, well I drank a lot of water this morning, and I think I washed it out, you know.

D: right, that’s good, you know the right and proper thing to do.

In the following excerpt, the elderly patient has been discussing with her GP whether she should give up driving. The GP’s response affirms the patient’s decision, puts it into context by suggesting that there are many people who manage without driving and also makes a practical suggestion that will help the patient “get out”.

D: right, lots of people have disabilities and they can’t drive and can’t catch buses, and like that, so you can get that, um... I think they might have the form out the front, if they do I can fill that out for you, because I don’t want you stuck with no way to get out, because that’s a bit demoralising isn’t it?

OP: yeah

D: but I think that the decision not to drive sounds like a reasonable one basically.

The overall encouragement that GPs gave to patients lent support to patient activities that maintained their physical and social activity and their embeddedness in family, and community life. However, there were examples in these consultations where doctors and patients negotiated an outcome rather than the GP either just affirming the patient or the patient accepting without question the GPs advice.
Doctors expressed sympathy and empathy less frequently than encouragement and it tended to be in an indirect manner. They might say something like “there are an awful lot of tests involved”, or “there’s a terribly long wait at --- “ rather than directly stating that they felt sorry for the patient for enduring the tests or the waiting.

Another less common category of themes involved doctors and patients discussing social, emotional and everyday contextual issues. As described these were sometimes taken into account when GPs gave practical advice. However, some doctors also spent some time discussing issues such as the approaching death of a close relative, a patient’s involvement in a support group or the difficulty in finding a suitable house. However, there were also occasions when doctors offered patients the opportunity to discuss such matters that were not taken up in great depth and conversely occasions where patients mentioned these sorts of issues and their GP did not acknowledge it or changed the subject to the more common subjects of medical consultations. An example of the latter is provided in the following short consultation in which a patient in the context of talking about his sore back mentions that his flat is damp because water is leaking into it. The GP expressed sympathy with the patient about this unfortunate incident but does not talk about whether the damp conditions may be affecting the patient’s sore back, or the broader context of the problem. The GP changes the subject to deal with the more immediate biomedical issue the patient has presented.

```
D: How is your back?
P: My back has been reasonably good but these last few days.... at the units, coming off the tennis courts and my flat is covered in water and it makes dampness, you know.
D: That is rather useless.
P: It is useless I have been in touch with the council but.....
D: ....... Now it is the Naprosyn that you need is that right?
P: That is right.
```

Less frequently occurring again was a group of themes that could be seen as social talk. They included such topics as current news events, the doings of family members (patients’ and doctors’), and shared acquaintances. Patients generally revealed more of their personal lives than their doctors but there were doctors in the study who talked about their families and referred to day-to-day aspects of their lives with their patients. These discussions frequently were also evidence of the familiarity with each other’s lives that marks a long term relationship between the GP and their patient. While there was evidence of friendliness between GP’s and their patients few showed evidence of friendship beyond the domain of the consultation.
Duration of Consultations

The duration of general practice consultations has important economic and health service ramifications. Recently in the UK Howie (1997) found that greater consultation length was related to greater patient 'enablement'. Enablement exists when people feel more able to deal with their health, their treatment and their life as the result of the consultation. People with chronic disease needed greater time to deal with the medical condition and to be enabled. Howie, Waitzkin and McWhinney have also identified ‘quality’ in GP consultations as dealing with the illness as well as the disease - the biopsychosocial as well as the biomedical (Howie, 1997, Waitzkin, 1994. The patient-centred model of care that is enabling deals with fears, facts and feelings (Stewart, 1995). Recently, Martin found that chronic disease consultations whether accompanied by a diagnosis of psychosocial problems were not a predictor of longer consultations in 2 large datasets and raised this as an issue of possible concern (Martin et al, 1997). However, little is known about the actual typology of chronic disease consultations and what patterns distinguish longer versus standard or shorter consultations. It is also interesting to note that consultations greater than or equal to 20 minutes are considered to be of ‘exceptional’ duration under the proposed new Medicare descriptors and that a new descriptor of 10-19 minutes is being proposed.

Therefore, we investigated the relationship between consultation duration and content with an emphasis on support processes in 106 chronic disease consultations. The consultations were divided into three groups: short (those less than 10 minutes in length), medium (those between 10 and 19 minutes) and longer (those 20 minutes and over) corresponding to the new consultation length proposed by the Relative Values Study and currently being commented upon by the profession. These groups of consultations were examined for differences in content and themes, or patterns of interactive talk between GPs and their patients.

The duration of consultations was: <6 minutes (3 consultations); 6-9 minutes (23 consultations); 10-19 minutes (47 consultations); 20+ minutes (33 consultations). They will be discussed in the following section as short consultations (those under 10 minutes, medium and longer consultations.

Consultation duration was measured both by actual time and numbers of lines of text. The distribution of consultations’ duration is described in Table 1. Very few were under 6 minutes, with the majority being 10-19 minutes. The ratio of standard to longer was approximately 2:1. This is in contrast with national data, where the ratio in chronic disease consultations was closer to 6:1 (Bridges-Webb et al, 1992).
The basic structure of consultations was similar no matter what their length and the four themes described above: (1) GP information giving, 2) GP review of treatment options, 3) GP review of the course and nature of medical conditions; 4) GP practical and lifestyle support, were important in all three groups of consultations. However, differences were apparent in the proportion of talk within these groups of consultations associated with these themes.

Table 1
Consultation Duration

<table>
<thead>
<tr>
<th>Duration</th>
<th>Frequency of consultations (n=106)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6 minutes</td>
<td>3</td>
</tr>
<tr>
<td>6-9 minutes</td>
<td>23</td>
</tr>
<tr>
<td>10-19 minutes</td>
<td>47</td>
</tr>
<tr>
<td>20+ minutes</td>
<td>33</td>
</tr>
</tbody>
</table>

Table 2
Major Themes and Consultation Duration

<table>
<thead>
<tr>
<th>Consultation Duration</th>
<th>&lt;10 minutes</th>
<th>&lt; 20 minutes</th>
<th>≥20 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme</td>
<td>Av. lines</td>
<td>%</td>
<td>Av. lines</td>
</tr>
<tr>
<td>GP review of treatment</td>
<td>46</td>
<td>35%</td>
<td>86</td>
</tr>
<tr>
<td>GP review of illness</td>
<td>38</td>
<td>29%</td>
<td>68</td>
</tr>
<tr>
<td>GP providing information</td>
<td>27</td>
<td>20%</td>
<td>58</td>
</tr>
<tr>
<td>Patient talk of illness</td>
<td>18</td>
<td>14%</td>
<td>29</td>
</tr>
</tbody>
</table>
The amount of text that was coded as GP initiated and led discussion was greater than that led by patients. The most dominant theme associated with patient’s talk was their descriptions and explanations of their illness. Patient’s discussion about their illness usually was part of an exchange with the doctor in which the reviewed the patient’s condition. We counted the number of lines associated with code words to indicate differences between consultations of different lengths. In the longer consultations roughly as much as text was associated with patients’ talk about their conditions as was associated with the review of patients’ conditions by their GPs in contrast with shorter consultations in which GP’s review of conditions dominated the talk and patients talked about their conditions roughly 50% less than GPs.

**Talk about Patient’s condition**

There are many factors that impact on the doctor patient relationship. Generally, it is acknowledged that GPs dominate the consultation process. Though questions have been raised about doctors’ diminishing status in Australia, research indicates that patients generally “prefer to retain a sense of trust and faith in the expertise and integrity of their doctors” (Lupton, 1997). Australians who are themselves professional or are tertiary educated are more like to be demanding than many patients in this study who were older, less likely to be tertiary educated, and women (see Lupton, 1997). This suggests that broader social and structural issues in the community impact upon the doctor patient relationship including the license the patient has to talk.

Differences between the way in which GPs and patients talk about the patient’s illness can be seen in the following sections taken from short, medium and long consultations. The excerpt from the following short consultation shows the way in which the GP can dominate the discussion of a patient’s condition so that the patient’s talk is not encouraged or is even “hindered” (Roter & Frankel, 1992). The GP lists a series of potential problems in quick succession so that at first the patient is not given the opportunity to respond. The patient is then verbally rewarded for being undemanding. By structuring the questioning in this rapid-fire way the patient is unable to present their illness narrative or to place their illness in a social context (Mishler, 1984 cited in Hyden 1997).
D: Okay I am going to just check your blood pressure. Any cough or phlegm? Staying away from the bugs, any indigestion?

P: No.

D: Bowels regular?

P: Yes

D: Waterworks alright?

P: Yes.

D: All systems go. Good on you, you lot never complain that is why I have to interrogate you. The younger ones come in with the first sniffle.

A GP who fails to encourage the patient to talk about all their concerns by actively listening and instead interrupts may obtain “an incomplete picture of the patient’s needs, resulting in an inappropriate treatment plan” (Roter & Frankel, 1992). This brief extract also illustrates the use of the closed question format. While closed and open ended questions elicit important medical information, open-ended questions do so more effectively because patients are “unconstrained to ‘tell their story’ and they divulged important medical information” (Roter & Frankel 1992). The amount of information that patients relay about their condition is understood to be related to the doctor’s control over question asking and that the GP’s questions sequentially lead the patient’s response to the questions (Roter & Frankel, 1992). These issues are related to the length of the consultation. If the patient talks more about her or his condition, consultations are likely to be longer.

However, while it is accepted that the GP “dominates the interaction”, (Hyden 1997) the brevity of a consultation or the concentration on the biomedical is not always the sole responsibility of the GP. Among the study consultations were those where patients attended consultations with specific, quickly satisfied requests such as to get a repeat prescription written. Another factor that may influence the amount of talk is the ongoing relationship between the GP and patient. Because the study consists of a series of consultations between GPs and the same patients it is possible to examine the patterns of consultation length between the same doctor and patient. Occasionally between the couple (i.e. doctor and patient) a medium or long consultation in which a problem or condition would be discussed in detail would be followed by a shorter consultation which would have a different purpose, such as to check how the patient was responding to the treatment discussed in the earlier, longer consultation. More commonly though, a series of consultations between the same patient and their doctor would be of similar length though they may fall into different duration categories (eg 1 consultation might be a short 8 minutes and the next a medium 11 minutes).
Length of consultation did not affect the central role of the biomedical discourse directed by the GP. It was still very much part of medium and longer consultations as the following exchange (medium length consultation) illustrates, although in this dialogue the patient gets more opportunity to talk about their condition than the previous shorter one.

*Dr*  *I will just have a look in your ear and, is your hearing affected on that side.*

*P*  *Yes I went deaf in that ear*

*Dr*  *So any change since you started having this pain.*

*P*  *No much the same, I can hear the whistling sound in it.*

*Dr*  *... something is going on there, it looks good. If I can find a sore spot. Is it sore around here?*

*P*  *No, it was the other day, it was right into the bottom of the neck there, it goes up into about there, it sort of starts and then works its way up behind the ear.*

*Dr*  *Also, when did you start getting this?*

*P*  *A couple of weeks ago, this started, I was very stiff on Sunday morning with it*

*Dr*  *Put your chin on your shoulder over here. The other way. It is a bit stiff. I suspect it probably is arthritis.*

In longer consultations patients were more likely to describe their symptoms in greater detail and participate more actively in reaching an understanding of the condition. In the following example of a consultation of over 20 minutes, the general practitioner encourages the patient to describe their symptoms in detail with questioning. The patient feels able to present a rich description of symptoms along with an interpretation of his condition in the context of his normal activities.

*D:*  *When you cough, do you cough stuff up?*

*P:*  *Not always but mostly yes.*

*D:*  *And when you do, have you looked at the colour, is it green or clear or ...*

*P:*  *No it is clear.*

*D:*  *How long have you been on Admenatek for?*
P: I went off it, I forgot to take it last Thursday and I didn't start until yesterday again but what prompted me to do it was (cough)

D: That is the sort of cough you mean?

P: I got this vicious headache, this vicious sinus headache that always comes when I come off it. What it does if I take half an Admenatek it keeps my sinus problem at bay. I know that it sounds peculiar..

D: Oh I believe you I just didn't.

P: It apparently must dilate everything and then when I go off it it all shrinks back down again and what happens is that the end of my nose at the start of the sinus cavity it must develop a very hard plug because if you go into an extremely humid .... like a steamy shower it all softens and you can feel it break away and it is right but the most disturbing thing is that if I don't get the headache in time then it doesn't matter. I could take tubs of codine phosphate and I never kill the pain.

In the above excerpt the patient introduces the topic of pain. This is often the subject of some of the longer sections of patient talk about their conditions. They frequently describe pain in particularly rich and detailed ways as the patient does in the following excerpt from a longer consultation. The patient could answer the GP's question by simply responding that his hand feels cold but instead he describes where the pain originates, how it moves, and what it feels like differentiating between the internal and external sensation of the pain as well as the desire to rip it out. Such a narrative does much more to help the GP determine what type of pain the patient is experiencing.

D: Yeah. Does it, um, feel particularly hot or cold?

P: Cold. Cold, yes. Many times that ??I start getting a pain that starts on that shoulder and its ?? and then I start getting it up here and down here and down here. And then it actually starts to, that's when I start taking tablets. Because by the time it gets down here I found out that then the pain is really bad. I think its in my hand. My hand gets so cold and I start to massage it and to try and get warm. But I feel real coldness in it and so, I go somewhere in the snow and you sort of stick your hand in the snow and keep it there for a while. You have to ??and I hit myself there, and I could see and I could feel the pain and all the rest of it. When the pain is disappears....I don't feel the pain in the....I don't feel the, I, I .if I could pull it out, that part of the flesh, the pain would be gone. You know what I mean? I mean, if you hit yourself you can feel the pain on top of the skin, or something like that, but this pain is inside. Its inside the flesh, and I think if I could only just go and rip that part out then the pain
wouldn't be there. Yet on the outside there's no pain, on the outside of the arm, its inside the arm. Its not, its funny, you see I don't feel this part, and I can just about put out a cigarette on there or poke myself with a needle, I don't feel it. But when it gets inside, I do feel it. And I feel the pain inside the hand. I don't feel anything. As you say I have a feeling like, well when someone (makes a gesture, noise in background) sort of a feeling like that.

Such vivid and detailed descriptions of the experience of pain were more likely to occur in longer consultations. However, patients talked not only about the experience of the pain itself but also how it impacts on their life. In the following excerpt from a short consultation the patient appears to be as much concerned that she could not get out of the chair as to the actual experience itself.

P: Okay, well everywhere else except on this side, the left side and I sat in that chair and I couldn't get up.

Acknowledgment has been made of the importance of psychosocial factors and social support in reducing morbidity, particularly for patients, such as those in the study with chronic conditions. In narrative terms this has been described as allowing into the consultations "the voice of the lifeworld." (Mishler, 1984 cited in Hyden 1997). In patient's descriptions of their pain, the opportunity to place their experiences in a social context become particularly important. Thus there are 2 issues; the pain itself and the management and continuation of the life that the pain is destroying or affecting. Patients seem to need to be able to express this pain and have the GP acknowledge it and understand it.

**GPs providing Information**

Other differences were apparent between the groups of consultations. As we have already discussed the provision of information by GPs was important in all consultations no matter what length but while GPs provided explanations in shorter consultations, they sometimes provided less detailed information.

D: You had a look at the report did you?

P: Yes.

D: Right they commented that there was some minor deterioration in the lumbar spine so it has got worse but not a lot worse than the previous one. Have you managed to organise any physiotherapy yet?

In this excerpt the GP moves on to questioning the patient about physiotherapy quickly thus discouraging the patient from asking for further explanation or from further discuss the subject further. It contrasts with the following excerpt of a more
detailed explanation from a longer consultation in which the GP talks about the physiology of the hip as well as explaining her concerns about the patient’s condition.

D: Well, have a seat, I think we definitely should check the hip joints because you are showing limitation in movement of the hip. A ball and socket joint and that is a model and you can’t because it is fixed but it rolls around on the the joint and if there is any problem with the joint you can't move. Now the two things I have in mind is whether in fact you might have had a fracture through there. I would have thought there would be much more pain than you have got, a very noticeable event but with the gate you have got after the surgery you might be having some irregular wear and tear on your joints so you may be having some arthritic type pain but because you have been immobilised for months I would have to be just a bit concerned about the cause of the pain but being male and being back up on your feet for quite a while that probably won’t be because males have much less a chance of osteoporotic bones. I won’t go into all that.

GPs see the ability to communicate well and to explain in simple terms as a necessary characteristic of a ‘good’ doctor (Lupton, 1997). Longer explanations and more detailed information if presented clearly is likely to provide patients with the knowledge they need to feel as though they are in control of their illness and that they are cognisant of all the options.

Review of treatment by GPs

Lines counts of the consultations indicate that the GPs review of treatment was an important component of all the consultations but that it took up a greater proportion of the short and medium length consultations in which less patient talk about illness occurred than in the longer consultations where the 4 major themes occupied fairly similar proportions of the consultations. The sections of text that were coded as GPs’ reviews of treatment were usually strongly biomedical in focus. It deals mainly with the very important and potentially life threatening area of prescribing regimes. It may be that if GPs have limited time when dealing with patients with chronic conditions that frequently involve complex prescribing regimes that this an area that they feel they need to concentrate on.

Less Important Clinical Themes

Table 3 shows the content and duration of themes that generally fitted the biomedical model but were less central to consultations. The content of these themes has been described earlier. There was little difference between the groups of consultations in the percentage of talk associated with each of these codes. In each group of consultations between 43 & 48% of the text associated with these codes was devoted to practical advice by GPs, between 24 and 27% to reviewing and discussing specialists and their advice between 17% and 22% to reviewing tests and between 3% and 11% to examinations by GPs.
Table 3

Less Important Clinical Themes

<table>
<thead>
<tr>
<th>Thematic Codes</th>
<th>&lt;10</th>
<th>10-20</th>
<th>&gt;20</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP practical advice</td>
<td>1.1</td>
<td>2.2</td>
<td>4.1</td>
</tr>
<tr>
<td>Review Specialist advice</td>
<td>0.7</td>
<td>1.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Review tests</td>
<td>0.6</td>
<td>0.9</td>
<td>1.8</td>
</tr>
<tr>
<td>GP Examination</td>
<td>0.3</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>GP practical advice 2</td>
<td>22</td>
<td>33.5</td>
<td>106.48</td>
</tr>
<tr>
<td>times/consult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review specialist advice</td>
<td>14.26</td>
<td>27.06</td>
<td>67.48</td>
</tr>
<tr>
<td>times/consult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review test</td>
<td>11.11</td>
<td>19.01</td>
<td>48.39</td>
</tr>
<tr>
<td>times/consult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP examination</td>
<td>1.38</td>
<td>12.31</td>
<td>13.54</td>
</tr>
</tbody>
</table>

Functional Social Support

Table 4 shows the number of times that codes that may be indicative of doctors providing functional social support for the patient are shown below. With the codes of encouragement, sympathy and empathy, only the number of times these codes occurred in consultation has been shown because usually they consist of a relative short piece of talk by a GP but they were coded to show the talk by the patient which elicited this response from the GP. The codes indicated that encouragement is used frequently by GPs in consultations of all lengths but more so in longer consultations.

Table 4

Emotional support by GPs

<table>
<thead>
<tr>
<th>Thematic codes</th>
<th>&lt;10</th>
<th>10-20</th>
<th>&gt;20</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP encouragement</td>
<td>0.8</td>
<td>1.2</td>
<td>1.69</td>
</tr>
<tr>
<td>GP sympathy</td>
<td>0.3</td>
<td>0.5</td>
<td>1.03</td>
</tr>
<tr>
<td>GP empathy</td>
<td>0.2</td>
<td>0.1</td>
<td>0.1</td>
</tr>
</tbody>
</table>
Table 5

Consultation Length and Psychosocial Codes

<table>
<thead>
<tr>
<th>Consultation Duration</th>
<th>&lt;10 minutes</th>
<th>10&lt;20 minutes</th>
<th>&gt;_20 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Av</td>
<td>%</td>
<td>Av</td>
</tr>
<tr>
<td>Thematic Codes</td>
<td>lines</td>
<td>lines</td>
<td>lines</td>
</tr>
<tr>
<td>GP raises social issue</td>
<td>11</td>
<td>99%</td>
<td>27</td>
</tr>
<tr>
<td>GP raises emotional issue</td>
<td>4</td>
<td>8%</td>
<td>7</td>
</tr>
<tr>
<td>Patient raises social issue</td>
<td>4</td>
<td>9%</td>
<td>9</td>
</tr>
<tr>
<td>Patient raises emotional issue</td>
<td>4</td>
<td>9%</td>
<td>3</td>
</tr>
<tr>
<td>Social talk</td>
<td>2</td>
<td>9%</td>
<td>8</td>
</tr>
<tr>
<td>Patient contextualises condition</td>
<td>7</td>
<td>15%</td>
<td>25</td>
</tr>
<tr>
<td>GP places themself in everyday context</td>
<td>16</td>
<td>17%</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 5 indicates that generally more time is spent on social issues than emotional issues in all lengths of consultations and that these are more likely to be GP led than patient led. There is no clear pattern that suggests that these codes associated with a narrowly defined functionally socially supportive are solely the province of longer consultations. However, the following table (Table 6) draws upon information collected in the patient surveys indicating that generally patients in the longer consultation group were more satisfied with their opportunities to confide in their GP than those in the shorter consultation groups. 1

1 The material included here on consultations analysed by duration has been presented at the ????? of the RACGP as work in progress. The use of number of codes and numbers of lines of code are used to indicate possible differences between consultations of different lengths. Further investigation of these differences are part of the future work proposed in this report.
14. Conclusion (implications/recommendations for policy, practice, future research)

It has been argued that social support is a complex concept or a meta-construct consisting of a number of distinguishable constructs. This study now has in place the ability to link patients' assessments of their social embeddedness, and their assessments of the support offered by their general practitioners. To date, we have investigated in particular one structural component of social support, namely consultation length.

Howie argues that consultation length is an important factor in consultations that increase the patient's chances of obtaining a better outcome which he defines as "enablement". In this paper he does not speculate on what it is that might occur in longer consultations that promotes enablement, although in his discussion of previous work he linked quality of care with consultation length. Doctors' levels of work stress, are associated with time pressures and less quality care. Another strand of relevant literature which he cites is the notion of holism and patient-centredness in general practice (Howie, Heaney, & Maxwell, 1997). We have examined the content of consultations in relation to their length. Longer consultations are distinguished by the likelihood that they contain more talk by the patient about their illness. We suggest that narrative theory offers lines of enquiry from which to investigate possible links between patient talk about their illness as a supportive component of consultations. GPs by allowing their patients the time and the opportunity to describe, analyse, and

---

Table 6
Consultation Length and Social Support

<table>
<thead>
<tr>
<th>Scale</th>
<th>Rating</th>
<th>&lt;10</th>
<th>10-20</th>
<th>&gt;20</th>
<th>Mixed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanted to confide</td>
<td>never/sometimes</td>
<td>50%</td>
<td>33%</td>
<td>33%</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td>often/always</td>
<td>50%</td>
<td>66%</td>
<td>66%</td>
<td>75%</td>
</tr>
<tr>
<td>Did confide</td>
<td>never/sometimes</td>
<td>50%</td>
<td>7%</td>
<td>20%</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td>often/always</td>
<td>50%</td>
<td>93%</td>
<td>80%</td>
<td>75%</td>
</tr>
<tr>
<td>Like to confide</td>
<td>never/sometimes</td>
<td>50%</td>
<td>44%</td>
<td>67%</td>
<td>45%</td>
</tr>
<tr>
<td>more</td>
<td>often/always</td>
<td>50%</td>
<td>56%</td>
<td>33%</td>
<td>55%</td>
</tr>
</tbody>
</table>

22
reflect upon their experiences of their illness are providing a supportive and beneficial environment. Narrative theory suggests that by allowing patients to talk about their condition allows them to construct a more positive identity and life for themselves (ref). However, it also simply allows the patient to provide the doctor with more information that places the patient’s medical condition in the context of their everyday life so that the GP may understand how the patient’s difficulties and what is the most usefully helpful.

The following figure illustrates our view of what may happen in consultations. The left hand side represents shorter consultations and the core biomedical features of those consultations. As consultations become longer more of the patients’ narratives of life and illness become part of the consultation process and the GP has more time to be supportive and to work towards outcomes beyond treatment adherence. We suggest that longer consultations provide social support to patients in two ways. The functionally supportive offering of sympathy, reassurance etc. can be accomplished fairly quickly (and perhaps mechanically) by GPs. Doctors who proffer social support in the form of detailed and comprehensible information and practical advice about a patient’s condition will take longer. We also suggest though that providing patient’s with opportunities to talk about their conditions at some length is, in itself, supportive.

Figure 1

Chronic Illness Consultations

Medical treatment, Health promotion, Social support

Patient narratives of disease and treatment, illness and life

Longer consultations

Enablement

Treatment adherence, Self-management, Coping, Healing,

Better disease control and quality of life
15. References


Roter, D., Frankel, R (1992) Quantitative and qualitative approaches to the evaluation of the medical dialogue Social Science and Medicine 34,10 1097-1103.


Appendix 4

Examples of Applications of Thesis Work

1. ACT Coordinated Care Trial -- (Draft) Social Support Guidelines

2. Core Curriculum RACGP Training Program -- Chronic Disease Management


---

1 As a member of a multidisciplinary working party

2 As a member of the RACGP National Council, I was influential in putting generic chronic disease and illness on the core Curriculum and was a very active member of the working party.

3 As a consultant to the RACGP I jointly wrote the manual with the Director of Education, Standards and QA. I provided the chronic care content. I am now Senior Medical Adviser to the Department of Veterans’ Affairs. I am developing an educational and support program in order to implement chronic care with a structure, process and appropriate remuneration general practice. I am currently setting up a controlled trial to evaluate the Department’s strategy for the elderly Veteran population. The question is – does care planning and chronic illness care incorporating support principles have a positive impact upon health status, service and drug profiles and health costs?

4 As Member of the Steering Group of the Better Evaluation of Australian Health Care project- the next version of AMTS survey analysed in my thesis in chapters 5, 6 and 7.
<table>
<thead>
<tr>
<th><strong>Glossary of terms</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACT</strong></td>
</tr>
<tr>
<td><strong>ANU</strong></td>
</tr>
<tr>
<td><strong>AMA</strong></td>
</tr>
<tr>
<td><strong>AMTS</strong></td>
</tr>
<tr>
<td><strong>ARI</strong></td>
</tr>
<tr>
<td><strong>Bulk-billing</strong></td>
</tr>
<tr>
<td><strong>Chronic care</strong></td>
</tr>
<tr>
<td><strong>CME</strong></td>
</tr>
<tr>
<td><strong>COAG</strong></td>
</tr>
<tr>
<td><strong>Community Health Centre</strong></td>
</tr>
<tr>
<td><strong>Consultation length and complexity in general practice fee-for-service items</strong></td>
</tr>
<tr>
<td><strong>Coordinated care trials</strong></td>
</tr>
<tr>
<td>Term</td>
</tr>
<tr>
<td>--------------------------</td>
</tr>
<tr>
<td>Divisions of General Practice</td>
</tr>
<tr>
<td>Extended hours clinics</td>
</tr>
<tr>
<td>Factor analysis</td>
</tr>
<tr>
<td>Fee-for-service</td>
</tr>
<tr>
<td>GEE</td>
</tr>
<tr>
<td>GP</td>
</tr>
<tr>
<td>Health Outcome</td>
</tr>
<tr>
<td>HIC</td>
</tr>
<tr>
<td>ICD-9-CM</td>
</tr>
<tr>
<td>ICIDH</td>
</tr>
<tr>
<td>ICPC</td>
</tr>
<tr>
<td>ICPC plus</td>
</tr>
<tr>
<td>IIS</td>
</tr>
<tr>
<td>Inner-city Melbourne</td>
</tr>
<tr>
<td>Category</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>Long-term care</td>
</tr>
<tr>
<td>Managed care</td>
</tr>
<tr>
<td>Medicare</td>
</tr>
<tr>
<td>MHI</td>
</tr>
<tr>
<td>NCEPH</td>
</tr>
<tr>
<td>Needs assessment.</td>
</tr>
<tr>
<td>NGO</td>
</tr>
<tr>
<td>NSW rural GP attenders</td>
</tr>
<tr>
<td>Private billing</td>
</tr>
<tr>
<td>Psychosocial</td>
</tr>
<tr>
<td>RACGP</td>
</tr>
<tr>
<td>RLS</td>
</tr>
<tr>
<td>RSI</td>
</tr>
<tr>
<td>SF-20</td>
</tr>
<tr>
<td>---------------</td>
</tr>
<tr>
<td>SF-36</td>
</tr>
<tr>
<td>SHG</td>
</tr>
<tr>
<td>Sick role</td>
</tr>
<tr>
<td>Social support.</td>
</tr>
<tr>
<td>SRH</td>
</tr>
<tr>
<td>UN</td>
</tr>
<tr>
<td>WHO</td>
</tr>
<tr>
<td>WHOQOL</td>
</tr>
<tr>
<td>WONCA</td>
</tr>
</tbody>
</table>