

# **EXPLANATORY MODELS OF ILLNESS AMONGST PRIMARY HEALTH CARE USERS IN MAMRE**

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A dissertation submitted in partial fulfilment of the requirements  
for the degree of Master of Arts in Clinical Psychology

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November 1992

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**ABSTRACT**

This study explores the illness experiences of twenty one patients who presented for treatment at primary health care settings in Mamre, a small "coloured" community approximately 50km from Cape Town, with the aim of investigating the possible contribution of psychological factors to presentation for primary health care. It also attempts to investigate how, psychologically, we may understand the process of illness identification and help-seeking. Selected literature on psychological issues in primary health care is reviewed. A hermeneutically-oriented medical anthropological approach to the study of illness and health care is outlined. The participants for the study were selected from all patients presenting at general practitioners in Mamre and for O.P.D treatment at Wesfleur hospital over a period of one week. A semi-structured interview, consisting mainly of open-ended questions and focussing on their illness explanations, experiences of treatment, and their understanding and/or experience of "nerves", was conducted within ten days, in their own homes. The analysis of the interview material drew on both quantitative and qualitative methodologies. The quantitative analysis provides indications of the frequency of types of illness and patient responses to treatment. The qualitative analysis draws on Kleinman's (1980) explanatory model framework with the aim of understanding the illness experience of each participant. The participants' understanding and/or experience of nerves is also described. This study provides additional insights in understanding the process of illness identification and help-seeking and the contribution of psychological issues in the presentation for primary health care.

<b>ACKNOWLEDGEMENTS</b>
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I would like to thank the following people:

Leslie Swartz, my supervisor, for his enthusiastic and generous support and guidance, and for his patience and fortitude in the face of sporadic attacks of 'nerves'.

Colleagues and students at the Child Guidance Clinic for their support and tolerance of my distraction with 'nerves' and explanatory models.

Friends and family for their encouragement and support over the past two years, and especially Ian, for his forbearance and for countless cups of tea; Didi, for her generous provision of a wonderful incentive; and Sue, for her careful and conscientious reading of the 'final' draft.

Tamzin for her editorial and layout assistance, and Priscilla for her administrative and other kinds of support.

And most importantly, the participants who so willingly shared aspects of their lives and experiences with me.

The financial assistance of the Institute for Research Development of the Human Sciences Research Council towards this research is hereby acknowledged. The opinions expressed, and conclusions arrived at are my own, and should not be regarded as a reflection of those of the Council.

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## INTRODUCTION

This study was undertaken as part of the initial phase of a broader project investigating psychological issues and the potential rôle of clinical psychological practice in primary health care in Mamre and similar communities. This study elicits explanatory models of illness of community members presenting for primary health care in Mamre, their ideas about nerves, and discusses the implications of these findings.

### 1.1 CONTEXT OF THE STUDY

Mamre, originally established as a Moravian mission station in the early 1800's, is a small community of about 5000 inhabitants situated on the Cape west coast approximately 50km north of Cape Town. The inhabitants are classified "coloured" and are largely working class. The community is characterised by a paucity of resources and poor socioeconomic conditions. The village is rapidly undergoing rural-urban transition owing to its close proximity to Atlantis and Cape Town and the installation of modern bulk services in the mid-1980's (Katzenellenbogen, 1988). Mamre's "rich history, transitional nature, close proximity to urban centres and fairly circumscribed location" (Katzenellenbogen, 1988, p.367) make it of interest to several academic disciplines, including health-related research.

The Mamre Community Health Project was established in the mid-1980's, with the aim of improving health in Mamre, and to develop an approach to health promotion which may be applicable to other similar areas (Swartz & Miller, 1992). As far as psychologists are concerned, the project currently employs a part-time clinical psychologist and a psychology intern. Community participation in the project was aimed at through a series of consultative meetings and the establishment of a joint steering committee (Katzenellenbogen, Pick, Hoffman & Weir, 1988). Demographic, social, environmental and health-related information was collected from approximately 5000 residents in 870 households in a baseline study in 1985/6 (see Katzenellenbogen, Joubert, Hoffman, & Thomas, 1988). The average household size was found to be 5.3, and when compared to Cape Town 'coloured' townships, Mamre falls within the 25% of areas with the highest level of overcrowding (Klopper & Tibbit, 1988). Of employable adults, 64.7% were working (78% of males and 87% of females), with most employment being offered in Cape Town and Atlantis in the semi-skilled and unskilled employment categories (Katzenellenbogen, Joubert, Hoffman, & Thomas, 1988). Since the

base-line study, however, there have been large scale lay-offs and closure of many businesses in Atlantis and Cape Town, as a result of a general downturn in the economy. Although current unemployment figures for Mamre are not available, unemployment is estimated to have risen dramatically. At the time of the base-line study, the community identified its problems as tuberculosis, poor sanitation, alcohol, dusty roads and an unsatisfactory water supply. Research revealed the most important morbidity issues to be tuberculosis, smoking and drinking, hypertension (in the older age group), rheumatism, and nerves (Hoffman, Pick, Joubert, Yach, Thomas, & Klopper, 1988). In the initial base-line study, nerves (*senuwees*) was used to denote mental illness, as the term is in general use amongst Mamre residents and was assumed to be a folk category roughly corresponding to the professional category of psychiatric illness (Swartz & Miller, 1992). However, the results of the pilot study, which revealed a high prevalence of nerves, suggested that the respondents were interpreting nerves more broadly than the researchers had intended (Swartz & Miller, 1992). As a result of the high prevalence of nerves reported in the pilot phase of the survey and the questions this raised about the relationship of nerves and psychiatric disorder, a clinical psychologist was invited to join the Mamre Community Health project. This resulted in a broadening of the focus of the research, to include not only a patient focus, but also a consideration of the problem, the situation and the organisation (See Swartz & Miller, 1992, for a more comprehensive discussion of the rôle of community clinical psychologists within a multi-disciplinary research team).

The international literature suggests that nerves and mental illness are not synonymous (Guarnaccia, DeLaCancela, & Carrillo, 1989). A later study which re-analysed the baseline health survey data for the Mamre population (Singer, 1990, cited in Swartz & Miller, 1992) found significant overlap between nerves and subjectively perceived ill health, and between nerves and hypertension. This suggests that nerves may serve as "an explanatory model for a range of misfortunes and distress" (Swartz & Miller, 1992, p.32).

The relevance of nerves for the present study will be discussed at the end of this introductory chapter. Prior to this, I will discuss the rationale for investigating psychological issues in primary health care, by discussing the presentation of illness in primary health care; the cultural construction of illness and the limitations of biomedicine, the concept of "explanatory models"; lay theories of illness aetiology; health care systems and patterns of help-seeking; aspects of the doctor-patient consultation; the issue of somatisation and folk illnesses.

## 1.2 PSYCHOLOGICAL ISSUES IN PRIMARY HEALTH CARE

Parry (1991) suggests that the political and economic changes in South Africa have resulted in policy changes in a number of areas, including health care, where there has been a shift towards primary health care and a decision to integrate mental health services into primary health care. The term 'primary health care' has been understood in two senses, the first narrower than the other. Schlebusch (1990, p. 302) has described primary health care as concerned with health care service delivery to local communities, with primary health care practitioners acting as referring agents to specialist hospitals and other services. This narrow definition of primary health care, then, defines the practice chiefly in terms of *location* of care. A broader definition of primary health care sees primary health care as a development strategy, involving curative medical care, preventive and promotive services, along with development programmes, and with a high degree of community participation and control (World Health Organisation, 1990). For the purposes of the current study, the narrower definition of primary health care will, in general be used. However the Mamre Community Health Project sees itself as involved in primary health care in the broader sense of the definition. The information gleaned from this study will be used to inform the Mamre Community Health Project's development approach, which includes the work of community clinical psychologists and community health workers. A second debate relevant to the current study is that of the relationship between primary health care and mental health care provision. Some researchers regard mental health care as a specialist service to which primary health care practitioners would refer, while others argue that mental health care should be fully integrated into primary health care (Swartz & Miller, 1992). This debate will not be entered into in any detail in this dissertation, but the findings will have relevance to further planning and debate about mental health services in Mamre.

It is well documented (Goldberg & Huxley, 1980; Shepherd, Wilkinson & Williams, 1986) that many patients presenting for primary health care are troubled by "psychological" rather than "physical" problems. Katon, Reis, & Kleinman (1984, cited in Parsons & Wakely, 1991, p.112) report that 68 - 92% of people seeking help from general practitioners do not have any serious disorder and many have no identifiable biological cause to their illness. Mechanic (1986, p.105) suggests that as many as 50% of people entering medical care present with symptoms which do not fit accepted classifications of disease (ICD-9) and that others are motivated in seeking care by problems and symptoms other than those they present. It is estimated that approximately 60% of primary health care involves people who are in fact

NB

experiencing "psychosocial" distress, although they present to the physician with physical symptoms (Katon et al., 1984, cited in Parsons & Wakely, 1991, p.112). The World Health Organisation (1990) suggests, on the basis of a review of a number of studies, that at least 20% of all presentations for primary health care are likely to be psychological in nature.

Psychiatric epidemiological studies provide more specific data regarding the prevalence of psychological disorders presenting in primary health care settings. In a review of South African psychiatric epidemiological research, Parry (1991, p.6) reports a likelihood of prevalence rates of at least 10% of adults in general health clinic samples, of conspicuous psychiatric morbidity (C.P.M. is the term used by researchers to provide an estimate of the number of people in need of mental health care, although not all would be classified as psychiatric cases). A summary of results of prevalence studies is presented in Table 1 below.

**Table 1: Prevalence of CPM in Southern Africa.**

Study	Region	Sample Type	Age	N	Apparatus/ Method	CPM%
Freeman (1980)	Kangwane (rural)	2	GE 65	139	SRQ/PSE	23.7%
Gillis et al. (1991)	Cape Town (urban)	2	GE 60	365	Short care	25.2%*
Hall & Williams (1987)	Zimbabwe (urban)	1	GE 16	448	SRQ	10.5%
Miller & Swartz (1991)**	Mamre (rural)	1	GT 15	159	GHQ 28	45%
Zwi & Thom (1991)	Soweto (urban)	1	16 60	301	SRQ/PSE	10.3-14.3%
Miller & Swartz (1991)	South Africa (rural)	1	GT 15	159	GHQ 28	45%
Zwi & Thom (1991)	South Africa (urban)	1	16 60	301	SRQ/PSE	10.3-14.3%

\* Depression Diagnostic Subscale of the Short Care

Adapted from Parry (1991, p.6).

\*\* A mixed race (so-called "Coloured") population. Other samples comprise black Africans.

Using the General Health Questionnaire which is recommended as a general screening instrument for mental disorders in general practice by Macdowell and Newell (1987, cited in Swartz and Miller, 1992), Miller & Swartz (1992) identified 45% of their sample in Mamre as potential "cases". This finding is high in relation to the rates reported by Freeman (1990) in Kangwane, and Zwi & Thom (1991) in Soweto. Parry (1991) reports CPM prevalence rates of 14 - 18% in clinic and community studies in other African countries.

### 1.3 MEDICAL ANTHROPOLOGY AND THE BIOMEDICAL MODEL

The separation referred to above of the "physical" or biological from the "psychological" or "psychosocial" reflects the assumption within biomedical knowledge and practice of the separation between the functioning (or malfunctioning) of mind and body (Lock & Gordon, 1988). This separation itself reflects Western cultural ideas about the duality of mind and body. The focus of the biomedical model is the diagnosis of somatic dysfunction and the linking of symptoms with underlying somatic/biological disorder, with the result that "symptoms achieve their meaning in relationship to physiological states, which are interpreted as the referents of the symptoms" (Good & Good 1980, p.170). This model "assumes that biologic concerns are more basic, 'real', clinically significant, and interesting than psychologic and sociocultural issues" (Kleinman, Eisenberg & Good, 1978, p.255). Although its potential in curing disease is acknowledged, the biomedical model has been criticised for its reductionism, its failure to include the personal and social context of sickness, and the meaning of the sickness for the patient and for those around them (Good & Good, 1980; Kleinman, 1980; McHugh & Vallis, 1986; Helman, 1990).

A number of attempts have been made to address the inadequacies of the biomedical model, which include the work of medical sociologists (Wright & Treacher, 1982, cited in Gaines, 1991) and the development of a 'biopsychosocial' model (Engel, 1977). A hermeneutic or interpretive medical anthropology attempts to address some of the problems of the biomedical model by approaching sickness as a "meaningful human reality", and clinical practice as "inherently interpretive or hermeneutic" (Good & Good, 1981, p. 174). More recently, Gaines (1991) has proposed the term 'cultural constructivism' which refers to the work labelled 'interpretive', 'hermeneutic', 'meaning-centred' and 'the explanatory model approach'. According to Gaines (1991, p.236) the "constructivist perspective takes culture [sic] history, meaning, human agency, human experience and responsibility as focal ... concerns, [and] seeks to locate contemporary illness experience in continuous cultural historical processes which serve to frame, interpret and give meaning to experience".

The concepts of "disease" and "illness" are distinguished; disease is defined as the malfunctioning of biologic or psycho-physiologic processes in the individual, whereas illness represents personal, interpersonal and cultural reactions to disease (Kleinman, Eisenberg & Good, 1978, p.252). There has been an historical shift in this definition, which is of particular relevance for the understanding of psychological problems. In more recent literature,

Kleinman (1986b, p.151) defines illness as "the human experience of suffering: the way the sick person and the members of his or her social network come to perceive, live with and respond to symptoms". This involves a "remaking or reworking of existing local beliefs and values as a response to the concrete contexts of personal experiences and actual social situations within which illness is embedded" (Kleinman, 1986b, p.151). Disease, by contrast, refers to the "process of interpretation which occurs where patients suffering from illness visit practitioners of one kind or another. Practitioners, as it were, reconstruct illness by refracting it through the theoretical lenses of their therapeutic professions" (Kleinman 1986, p.151).

It is thus possible to have disease without illness, for example, in the presence of a tumour, when the patient may not yet have experienced symptoms. Illness may occur without disease, when complaints have no measurable biological basis. In most sicknesses, however, disease and illness occur together and reciprocally influence each other (Kleinman, 1977).

#### **1.4 CULTURE AND ILLNESS**

The hermeneutic approach suggests that becoming ill is a social process. The experience of illness is mediated by language, beliefs about illness, socially learned ways of behaving when ill, (Kleinman, 1988a) and the personal significance of pain and suffering (Good, Brodwin, Good & Kleinman, 1992). The responses and interpretations of the patient's family and social environment are also implicated, and, as Helman (1990) notes, their co-operation and acceptance is needed for the person to adopt the rights and benefits of the sick role. Furthermore, Kleinman (1988a) notes, professional and lay interpretations of experience are communicated within particular relationships of power, which also affect the illness experience. One aspect of this is the importance, for the patient, of the validation of the sick role by a medical professional (see Reid, Ewan and Lowy, 1991). Illness experiences therefore, are embedded in social relationships and the cultural context in which they occur. NB

In the same way that illness experiences and behaviour are culturally and socially embedded, so too is the knowledge and practice of biomedicine, which is described as "a culturally constructed professional ethnomedicine" (Gaines, 1991). As Good & Good (1981) explain, all clinical practice is fundamentally interpretive; the practitioner draws on particular models which may include biochemical, immunological, viral, genetic, environmental, psychodynamic, family interactionist, or pharmacological approaches - in order to interpret the symptoms presented by the sick person as signs of particular disease states. However, as Helman (1990)

points out, the medical model should not be seen as homogenous and consistent; clinical practice may be influenced by the doctor's personality, training, speciality and experience, as well as the socio-cultural context of the consultation. In addition, it is suggested that local cultural norms significantly influence professional culture (Townsend, 1978; Gaines, 1979, 1982; cited in Kleinman, 1986, p.152).

The hermeneutic approach has been criticised for its focus on 'microlevel' issues, and its neglect of the political economy of health (Baer, Singer & Johnson, 1986; Singer, 1989). Gaines (1991) argues that 'critical' medical anthropology's attempts to relate medical ideas causally to social, political and economic circumstances is mechanistic. Gaines (1991) further suggests that political economic theories fail to predict local level realities, and do not address the 'determinants' of health and sickness. Furthermore, it is argued that the assignation of the term 'micro-level' as the focus of the 'social constructivist' anthropologists is inapplicable. Gaines (1991, p.238) states that the foci of 'constructivist' research - "culture, history, social classificatory systems, status systems, systems of purity and pollution, conceptions of person, theories of the body, of experience and suffering, ethnophysiology and ethnoanatomy, local health care systems, and systems of power are all key conceptions and foci for understanding and interpreting medical experiences".

For reasons of space, this debate will not be further discussed. Suffice to say that both interpretive and political-economic analyses are necessary in understanding the relationship between broader structural aspects of health care on the one hand, and clinical practice and subjective experience of illness and health care, on the other.

## **1.5 EXPLANATORY MODELS**

The "explanatory model" (Kleinman, 1978, 1980, 1986, 1988b) is a conceptual framework which provides a means of understanding the process by which illness is patterned, interpreted and treated (Helman, 1990). Explanatory models are defined as "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman, 1980, p.105). They offer explanations of sickness and treatment which guide choices among available resources and which cast personal and social meaning on the experience of sickness. Kleinman (1980) distinguishes between explanatory models and general beliefs about sickness and health care; explanatory models are constituted in response to particular illness episodes. The explanatory model generally provides

explanations of different dimensions of the sickness. These are: aetiology; timing and mode of onset of symptoms; pathophysiology; course of sickness, including degree of severity and type of sick role; treatment issues; fears and problems associated with the illness. It is suggested (Kleinman, 1980) that there are significant differences between lay and practitioner explanatory models. Whereas practitioner models deal with most or all of these aspects, patient and family models focus on the significance of a given health problem for the patient and his/her family, and on treatment goals. Lay explanatory models are characterised by "vagueness, multiplicity of meanings, frequent changes, and lack of sharp boundaries between ideas and experience" (Kleinman, 1980, p.107), and may incorporate personal, popular and professional health beliefs and experiences. The construction, adjustment and transformation of illness explanations is an ongoing process, occurring within the context of the social environment and life circumstances (Hunt, Jordan & Irwin, 1989).

In his more recent work, Kleinman (1988b) focuses on the illness narratives of patients suffering from chronic illness and pain. The narrative is used by the chronically ill person to create meaning and to give order to events and experiences; it is reconstructed and revised, in the light of changes over time. "Patients order their experience of illness - what it means to them and to significant others - as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering" (Kleinman, 1988b, p.49). As a result of the long and often unpredictable course of chronic illness, the illness narrative functions not only to reflect the illness experience, but also to shape and even create experience.

Saillant (1990) has described the cultural aspects of the experience of cancer. Within the modern clinical context and the mass media, discourse on cancer has shifted in the last decade from death to **survival**, and it articulates themes of maintaining hope and morale. Saillant (1990, p.83) suggests that "within the context of their experience of illness, patients produce a knowledge which integrates its related causes, processes and representations. The content of this knowledge ... both personifies causes and gives creative coherence to illness. In other words, popular knowledge about cancer produces meanings that enable symbolisation of the survival experience".

Kleinman (1988b, p.50) also describes the phenomenon of "retrospective narratisation", viz. that in order to provide "significance and validity in the creation of a life story", the actual events of the illness experience may be distorted or reworked. For example, in situations

where illness has had a "catastrophic end", the narrative may serve a moral purpose, to reaffirm values and give meaning and finality to a loss; or it may function as a political commentary on perceived injustice or oppression (Kleinman, 1988b, p.51).

The concept of explanatory models has been criticised for making assumptions about the rationality of behaviour and for reliance on cognitive factors in the experience of illness (Young, 1981). Kleinman (1981, p.374) argues that illness is inseparable from the networks of meanings within which it is experienced and treated, and that these meanings "remain dense, vague, obscure and partially interpreted or misinterpreted ... [and] they are only partially out of awareness". The explanatory model approach focuses on the meanings of the illness within the patient's personal and social world, and discloses "the interpersonal processes of denial and dissimulation, retrospective narratisation and rationalisation, dependence and domination, reality construction and manipulation" (Kleinman, 1981, p.376). It is asserted that the explanatory model functions as a practical statement about particular illness experiences (Kleinman, 1981), and as a useful clinical instrument and teaching and research device, rather than as a theoretical concept (Blumhagen, 1982).

## 1.6 LAY THEORIES OF AETIOLOGY OF ILLNESS

As noted earlier, Kleinman (1980) distinguishes between explanatory models, which are constituted in response to particular illness episodes, and general beliefs and theories about sickness. Helman (1990) describes lay theories of illness as based on beliefs about the functioning of the body and broader concepts about the origins of misfortune. In a review of lay theories of the aetiology of ill-health, Helman (1990, pp.103 - 110) proposes the following categories for the location of aetiology: within the individual patient, in the natural world, in the social world, or in the supernatural world. These will be discussed in turn, with the understanding that these categories are not mutually exclusive; different aspects of each may constitute an individual's belief system.

*The patient:* Theories which locate the origin of ill health within the individual focus mainly on malfunctions within the body, and are associated with changes in diet or behaviour. (An example of this would be "hyper-tension" or "high pressure", as described by Blumhagen, 1982). The responsibility for the illness therefore is attributed to the patient "for not taking care" of oneself (Helman, 1990, p.104).

onset of illness. They tend to produce a narrative of the illness concerning events in the patient's social environment and relationships. The strength of the externalising systems lies in their potential to provide explanations and meanings, whereas the strength of the internalising systems is their ability to organise symptoms into diagnoses about underlying pathophysiological processes (Young, 1983, p.1206).

## **1.7 SYSTEMS OF HEALTH CARE AND PATTERNS OF HELP-SEEKING**

Kleinman (1980, p.24) suggests that the different components of health care within a society may be viewed as a cultural system, "a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions". Health care systems, therefore, may be conceptualised as the combination of beliefs about illness, healing activities, ideas about and expectations of treatment, clinical settings and institutions, roles and status relationships. Gaines (1991, p.243) describes medical systems as "novel recombinations of existing ideological and practical elements of the local culture and, in some cases reworked elements from other cultures". In addition to cultural influences, health care systems are shaped by political, economic, historical and environmental factors.

Kleinman (1980) describes three structural domains of health care: professional (biomedically trained), folk (non-professional healers) and popular (family, social network and community). Each area has its own explanatory systems, social roles, interaction settings and institutions (Kleinman, 1978). Most health care and health maintenance takes place within the popular sector. The popular sector functions as "the chief source and most immediate determinant of health care" (Kleinman, 1980, p.51).

Patterns of help-seeking vary according to a range of factors, including the evaluation of symptoms, patient and family beliefs about and prior experiences of illness and treatment (Kleinman, 1980), perceived interference with personal relationships, work activities or physical functioning, availability of health care services (Zola, 1973), class and gender. Helman (1990) suggests that the decision to seek medical aid is influenced by social, cultural and emotional factors, rather than the severity of the illness.

## **1.8 ASPECTS OF THE DOCTOR-PATIENT CONSULTATION**

Within each domain of health care, the categories used in the perception, expression and evaluation of symptoms, result in illness being cast within a particular cultural form, which

Kleinman (1980, p.72) terms "the cultural construction of clinical reality". Disease and illness, therefore, are viewed as explanatory concepts rather than entities. The "cultural hermeneutic model" (Good and Good, 1980) suggests that appropriate clinical practice involves attempting to understand the meaning of the illness for the patient. Kleinman (1988b) has identified specific layers of illness meaning: firstly, the conventional, overt meaning attached to a symptom, for example that a breast lump might signify cancer; secondly, the cultural significance of particular symptoms within particular social contexts; thirdly, the significance of illness within the patient's life world, which includes both the interpersonal and intrapersonal worlds; and lastly, explanation and emotion as meaning, which refers to the explanatory accounts, interpretations and affective responses of the patient and his or her social network.

Kleinman (1986, 1988b) suggests that the task of the practitioner is to elicit the patient's explanatory model, to interpret the different layers of meaning by exploring the personal and family histories and the social context. The practitioner's explanatory model should also be presented and discussed, and the treatment of both illness and disease negotiated with the patient and the family. In cases where effective interventions are not available or applicable, the practitioner's assistance to the patient and family in making sense of the illness experience is invaluable. As Kleinman (1988b, p.50) explains "for the care giver what is important is to witness a life story, to validate its interpretation, and to affirm its value". This is particularly important in cases of chronic illness or pain, where the "ontological assault", the disruption of the taken-for-granted world of everyday life fundamentally affects the concept of self, the relationship between self and body, the performance of activities and results in continuing reconstruction of past, present and future (Good, Brodwin, Good & Kleinman, 1992, p.104).

## **1.9 SOMATISATION AND FOLK ILLNESSES**

Kleinman (1982, p.129) defines somatisation as "both the expression of physical complaints in the absence of defined organic pathology and the amplification of symptoms resulting from established organic pathology". It is conventionally associated with anxiety disorders and depression, and has been reported "in the absence of psychopathology as an expression of and means of coping with social stress and personal distress" (Kleinman, 1982, p.129). Kirmayer (1986) suggests that somatisation is rooted in a conflict between competing interpretations of illness; whereas the patient experiences his/her problems as somatic, and presents with physical complaints, health-care providers perceive the problem as relating to psychological or

social difficulties. Kirmayer (1986,p.111) argues that somatisation "cuts across diagnostic categories and is best considered the result of processes that shape the experience and expression of every illness episode". In psychosomatic disorders, as with other disorders, it is necessary to understand these processes, which influence both patients' and practitioners' interpretations of the disorder, and how these processes are derived from the socio-cultural milieu. Helman (1988, p.101) suggests that "the social and cultural worlds ... provide the categories through which both bodily and psychological experiences are perceived and interpreted". For example, health-care systems and family and social networks may sanction the expression of bodily symptoms by providing care and support, while the experience of psychological distress may be stigmatised (Kleinman, 1982). Kirmayer (1986) concludes that somatisation is irreducibly social in nature.

Earlier cross-cultural psychiatric research (Leff, 1981, cited in Kleinman, 1982) suggested that somatisation is more common in a number of non-Western societies, and amongst poor and working class populations. This is disputed by other writers (Kirmayer, 1988; Parsons & Wakely, 1991; Scheper-Hughes, 1992), who argue that somatisation is equally common in Western industrialised societies. Psychologisation, where patients focus on the emotional and intrapsychic issues, is generally put forward as the obverse of somatisation. Kirmayer (1986, p.129) argues that "somatisation and psychologisation may be understood as contrasting methods of constructing illness meaning that assimilate emotional experience to either the bodily or social realm".

Scheper-Hughes (1992, p.9) criticises medical anthropology for its continuing use of the somatisation model, arguing that "If mind and body are truly one, as even the most conventional medical anthropologists assert, then *all* diseases, without exception, are and must be psychosomatic - all are "somatized" as well as "mentalised" ... Moreover, people *everywhere*, men as well as women, and people of *all* social classes, employ their bodies in expressing complicated, contradictory, and hostile sentiments".

It has been noted that individualistic psychological theories (Kirmayer, 1986) and biomedical practice (Scheper-Hughes, 1992) may function to divert attention from the broader socio-economic and political forces which contribute to all forms of distress and disease. Scheper-Hughes (1992, p.8) suggests that illness functions as a "culturally rich" form of communication within oppressive societies, where overt social protest is not tolerated: "Some forms and expressions of illness, disability, and madness may be viewed as acts of embodied refusal, as

mockery, and as protest by the relatively powerless against oppressive social roles and ideologies". She (1992, pp.11 - 12) describes the afflictions of agricultural wage labourers in Brazil, where "socioeconomic and political contradictions often take shape in the 'natural' contradictions of angry, sick and afflicted bodies ... (and) the nervous-hungry, nervous-angry body of the cane cutter offers itself as a metaphor and metonym of the nervous socio-political system and for the paralysed position of the rural worker in the current economic and political disorder".

Somatisation has been described (Helman, 1990) as an aspect of folk illnesses, which are defined as "syndromes from which members of a particular group claim to suffer and for which their culture provides an aetiology, a diagnosis, preventive measures and regimens of healing" (Rubel, 1977, cited in Helman, 1990, p.97). Examples of folk illnesses are *amafufunyana* in South Africa (Ngubane, 1978), "heart distress" in Iran (Good, 1977), *nervios* in Costa Rica (Low, 1981) and *high blood* in the U.S.A. (Blumhagen, 1982). Helman (1990, p.97) suggests that folk illnesses have a range of symbolic meanings, moral, social or psychological, which link the suffering of the individual to changes in the natural environment, supernatural forces, or serve as culturally accepted indications of social conflict or disharmony. A folk illness especially relevant to the present study is "nerves".

### B1.1 NERVES: AN INTRODUCTION

As mentioned earlier in this chapter, the 1986 survey of health status in Mamre reported a high prevalence of nerves (Miller & Swartz, 1990). Primary health care practitioners were consulted for nerves (Miller & Swartz, 1990). Questions pertaining to the nature and treatment of nerves in Mamre and the relationship between nerves and psychiatric disorder suggest that nerves is an important issue in the investigation of psychological issues in primary health care.

Nerves are interpreted in the international literature as an expression of distress resulting from familial, cultural and socio-economic difficulties and disruption (Low, 1988; Dunk, 1988; Guarnaccia, DeLaCancela & Carrillo, 1989; van Schaik, 1988; Davis & Low, 1989). In a seminal article on nerves, Low (1985) defined nerves as an important culturally interpreted syndrome: although nerves across cultures may have certain features in common, the content and expression of nerves is specific to regional, cultural and individual contexts. Lock (1991, p.90) suggests that nerves are understood as a "metaphor for the structural inequalities of

gender, class and ethnicity inherent in the societies under study". However, she argues that the analysis of nerves as an expression of distress may be extended to an interpretation of nerves as a form of resistance - "products of and reactions to the dominant ideology" (ibid.). Despite the fact that few nerves sufferers articulate a clear relationship between nerves and the dominant ideology, their association of their suffering with oppressive working conditions and social relations suggests that they are "alert to the social and political origins of their problem" (Lock, 1991, p.89).

## **B1.2 NERVES AND GENDER**

In the preface to a collection of studies investigating different aspects of the relationship between gender and nerves, Davis & Low (1989) state that although gender affects the mode of expression of nerves, the experience of nerves is not necessarily gender-specific. It is suggested that gender roles influence the way that nerves functions in women's lives; that suffering from nerves provides various secondary gains for women. These may take the form of increased social support, release from culturally defined gender roles and enhanced power and social status (Krieger, 1989; Finerman, 1989). However, suffering from nerves may also have socially negative consequences for women. Davis & Low (1989) suggest that in some contexts, nerves may reinforce negative aspects of cultural roles and result in isolation and diminished support. In addition, the process of labelling emotional and social problems as nerves may result in the medicalisation of what are essentially political and socioeconomic, rather than individual, problems (Davis & Low, 1989).

## **B1.3 NERVES AND MENTAL ILLNESS**

Much of the international literature on nerves suggests that nerves are distinguished from mental illness by their informants (Low, 1981; Guarnaccia, DeLaCancela & Carrillo, 1989; van Schaik, 1989; Dunk, 1989). Davis & Guarnaccia (1990, p.7) suggest that nerves becomes an illness only under certain social conditions, rather than when a threshold of symptoms is crossed. However, there is some disagreement about a clear distinction; Low (1988, p.415) states that "the concept of *nervios* provides a socially sanctioned vehicle for the expression of distress, *and in some cases, mental illness*, (my emphasis) that in other situations would be stigmatized". In a cross cultural comparison of conceptions of schizophrenia, Jenkins (1988, p.1241) reports that within Mexican - American families in her study, *nervios* served as a culturally salient interpretation of what had been diagnosed as schizophrenic illness.

In an investigation of the relationship between nerves and mental illness in Mamre, Miller & Swartz (1990) found that half the psychiatric patients and half of the relatives of psychiatric patients reported suffering from nerves. This suggests that nerves does not refer only to psychiatric illness. It is suggested that nerves may be "a metaphor for emotional distress" in a broader sense than that described by mental illness (Miller & Swartz, 1990, p.5).

#### **B1.4 PSYCHOSOMATIC ILLNESS AND NERVES**

Nerves has been described in terms of "somatisation" (Dunk, 1989) and as "psychosomatic illness" (Krieger, 1989). Somatisation, like nerves, has been interpreted as an expression of, and a means of coping with, social and emotional distress, often by women in relatively powerless positions (Nichter, 1981). Dunk (1989) argues that the way in which distress is expressed is culturally constructed: for the Greek-Canadian women in her study, gender differences in terms of appropriate behaviour and expression explain why women presented with *nevra* more often than men.

#### **B1.5 PREVALENCE AND INCIDENCE**

Most of the studies of nerves focussed on qualitative rather than quantitative data, and therefore did not assess prevalence. However, there are some notable exceptions. In a study conducted in urban outpatient clinics in San José, Costa Rica, Low (1981) reports that *nervios* was found to be the presenting complaint in 30% of general medical consultations, and 50% of psychiatric consultations. In a second study in a *colonia* outside Guatemala City, which focussed on child growth and development within the poorest of socioeconomic conditions, Low (1989) surveyed 322 families. From a total of 515 individual cases, comprising 308 females and 207 males, 322 or 62,5% reported having *nervios*. Women comprised 83% of the *nervios* cases. Finerman (1989) documented 154 cases of *nervios* out of 2460 illness episodes reported by Saraguro Indian women in Ecuador, a prevalence rate of 6,3%. *Nervios* was found to be the sixth most common health complaint, and the third most common complaint for adult women in the survey. Finerman (1989, p.52) reports that "virtually every research subject" was found to have suffered at least one episode of the disorder during the year long study.

## B1.6 THE NATURE OF NERVES: SYMPTOMS AND AETIOLOGY

Studies of nerves/*nervios/nevras* across a range of cultural settings report overlapping symptomatology, and aetiologically it is associated with a range of social, emotional and physiological conditions and experiences. Studies which were felt to be pertinent to the issue of nerves in the Mamre context will be briefly reviewed.

In a study of *nervios* in Costa Rica, Low (1988) reports that *nervios* is associated with family interactional discord, disruption of family structure, and past family disturbance. *Nervios* was presented both as a symptom, a single complaint or sign of psychosocial discomfort, and a syndrome, a culturally labelled grouping of related symptoms. Symptoms associated with *nervios* were, in order of frequency, headache, insomnia, lack of appetite, depression, fears, anger or bad character, trembling, disorientation, fatigue, itching, altered perceptions, profuse sweating, lifelessness, vomiting and hot sensations.

Van Schaik (1989), in a study of nerves in Eastern Kentucky, reports that the symptoms described by her informants included feelings of nervousness, anger, impatience, fearfulness and depression, as well as insomnia and crying. Informants also reported a range of somatic complaints, including gastrointestinal disturbances, weight loss, increased heart rate, elevated blood pressure, headaches, "smothering" and "blackouts". Differing combinations of the above symptoms were reported; the only symptom reported by all informants was some form of physical agitation or restlessness. The informants identified family difficulties and conflicts, frequently exacerbated by financial problems, as the source of their nerves.

In her study of Greek immigrant women in Montreal, Dunk (1989) reports that *nevras* was inevitably described as a physical complaint, which sometimes included headaches, dizziness and pain, and was often accompanied by feelings of melancholia, anger or *stenochoria* (distress, worry). *Nevra* was associated with a feeling of loss of control. Dunk (1989) reports that most of these patients articulated a breakdown in family relations, the pressures of the competing roles of homemaker and worker for those doing piece-work at home, work stresses for those employed outside of the home, the comparatively difficult cold climate of Montreal after the warmth of Greece, and the general pressures of life as an immigrant, as the reasons for their nerves.

Guarnaccia, DeLaCancela, & Carrillo (1989) reconceptualised the *ataques de nervios* in the Latino community, and suggest that *nervios* is an expression of anger and sadness resulting

from the disruption of traditional family systems, the process of migration, and worry about family members they have left behind. The symptoms are usually experienced as an acute episode, and may include shaking, heart palpitations, feelings of weakness, difficulty moving their limbs, and loss of consciousness. Nerves sufferers may also become violent and abusive.

In her study of *nervios* in Guatemala, Low (1989) reports that *nervios* is associated with strong emotions, particularly anger, grief or sorrow, and with problems around reproduction and childrearing. Symptoms associated with the incidence of *nervios* included (in order of frequency) headache, despair or desperation, face pain, trembling, anger, anxiety, twitching or jerking of the body, stomach pain, high blood pressure, body pain, itching and insomnia.

Finerman (1989, p.142), in a study of *nervios* amongst Saraguro Indian women in Ecuador, reports that *nervios* takes the form of "a stress-related syndrome exhibiting symptoms characteristic of depression". The most common symptoms included profound sadness; loss of appetite, sleep, and interest in work and family; fatigue, headaches, mental confusion and poor concentration; trembling, physical agitation and tension; menstrual irregularity; fits of crying; nightmares; body aches; irritability and stomachaches. The primary cause of the disorder is suffering (*sufrimiento*) which is attributed to personal or family illness or death, domestic discord, sudden fright or shock, malicious gossip, or financial problems. Finerman (1989, p.50) suggests that the disorder is related to women's efforts to maintain social and economic power, the pressures of meeting gender role demands and unrealistic expectations of family and community.

### **B1.7 FUNCTION OF NERVES: EFFECT ON SOCIAL RELATIONSHIPS**

According to Low (1988, p.415) the concept of nerves "helps organise a diverse series of complaints into a culturally meaningful unit, that physicians recognise and treat and that the people around the patient accept as a regular, although not normal, reaction to the stress of family disruptions and other disturbances of everyday life". Some research, particularly that pertaining to gender and nerves (Low, 1988; Clark, 1989; Finerman, 1989; Krieger, 1989), has focussed on the role of nerves within social relationships.

Low (1988) suggests that the presentation of *nervios* absolves the individual of responsibility and provides a culturally acceptable idiom of distress. Specifically, Low (1988) suggests that the syndrome elicits a positive response from family members and significant others, usually in the form of increased attention, help with daily tasks, and expressions of concern and

support which may help to resolve the underlying conflict. This is supported by Clark (1989) in her study of nerves in Methana, Greece, where *nevra* may be a means of gaining sympathy and support and possibly even of bringing about some change in the relationship to source of distress. Krieger (1989, p.92) describes the "social use" of emotional and physical symptoms of "upsetness" amongst working class women in Cairo. Women publicize their *nerfiza* or emotionally caused illness in order to put social pressure on the person causing their upset, and to rally support for themselves. Krieger (1989) gives the example of a woman who used her symptoms to change her husband's behaviour towards her, and to get emotional support from her community following the death of her son.

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Finerman (1989) reports that amongst Saraguro women, *nervios* may also function as a means of escaping from intolerable difficulty, while retaining their status within their social network. Her informants insisted that *nervios* sufferers should not be blamed for their condition; the disorder is regarded as proof that "the victim was tried beyond <sup>nerves</sup> endurance by adversity, and fell ill from his or her own suffering" (Finerman, 1989, p.57). The appropriate response to this was that *nervios* sufferers should be treated sympathetically and relieved of their responsibilities. The effect on household members of having to take on all her duties would be increased appreciation of and recognition for the woman concerned of her role in the household.

## B1.8 TREATMENT AND MEDICATION

Discussion of treatment has addressed the issue of the medicalisation of nerves (Dunk, 1989; Guarnaccia et al., 1989; van Schaik, 1989; Finkler, 1989; Lock, 1991) which masks its social origins and does not resolve the underlying problems. Dunk (1989) suggests that the unwillingness of her informants to consult social workers or psychologists, and the inability or unwillingness of doctors to respond to the underlying social and material problems tend to result in the medicalisation of *nevra*, which does not address the difficulties giving rise to the *nevra*. Dunk (1989) reports that most of her informants' expectations of treatment were for the doctor to be a sympathetic listener. This is supported by Guarnaccia et al., (1989) who report the need for emotional support for nerves sufferers, as the traditional support networks were no longer available to them. Van Schaik (1989, p.19) criticises the biomedical model for its focus on symptomatology which "precludes questions of possible social aetiology and mystifies the answer to 'what is really bothering' individuals complaining of nerves". Finkler

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(1989) criticises biomedicine in North America for medicalising nerves by prescribing pills upon which patients become dependent. k/s

Some studies report a reluctance to consult medical practitioners; Finerman (1989) reports that Saraguro women treated more than 85% of all reported *nervios* episodes with home-based care, which included plant remedies and family support. These women maintained that practitioners were ineffectual in treating nerves successfully (Finerman, 1989). A similar view was held by the Greek immigrant women in Dunk's (1989) study, who reported that they did not believe that medication resolved the basic problem, although the prescription of pills was reported to be the most common form of treatment (Dunk, 1989, p.32). Low (1988) describes a pattern of treatment, which begins with home remedies, and is followed by treatment from a pharmacist or herbal practitioner, which may lead to consulting a physician, general practitioner or psychiatrist. If this is unsuccessful, the patient may seek specialised or private medical care.

According to Low (1988) Costa Rican patients expect some kind of explanation of their illness and medication in all medical encounters. She reports that physicians accept *nervios*<sup>pain</sup> as a valid symptom and respond positively to the patient's request for attention. The diagnosis may be recorded as depression or anxiety, ie. a medical diagnosis. The treatment is a conversation about its cause, and validation and treatment of the symptom or distress experienced by the patient with a prescription of tranquilliser or antidepressant. 100  
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### C1.1 AIMS OF THE CURRENT STUDY

This brief review of the literature has outlined the central concepts of hermeneutically-oriented medical anthropology, described Kleinman's (1986) framework for the understanding of 'explanatory models', discussed lay theories of illness aetiology, health care systems and patterns of help-seeking, aspects of the doctor patient consultation, somatisation and 'folk illnesses', and selectively reviewed the literature on nerves. This will serve as a theoretical background to the investigation of the explanatory models of patients presenting for primary health care in Mamre, with the aim of understanding the meanings of their illnesses for these patients, their responses to treatment, and their understanding and experiences of nerves and mental illness. It is hoped that this study will contribute to the understanding of psychological issues in primary health care and to the development of appropriate clinical practice.

## **METHODOLOGY**

### **2.1 BACKGROUND TO THIS STUDY**

Participants in this study were selected from a larger project investigating psychological issues in primary health care. The design and method of this larger study will be briefly outlined, as it formed part of the process of selection of subjects for the present study.

Every Mamre resident who presented for treatment at primary health care contexts for the first week in September 1990 was asked to participate in the study. As previously described, primary health care for Mamre residents is provided by general practitioners, district surgeons and Day Hospital or Out Patient Department treatment at Wesfleur Hospital, in Atlantis, 7 km away. In cases where patients were under 15 years of age, or were brought in by a caretaker, the caretaker was constituted as a respondent for the purposes of the study, as the literature suggests that it is the mental state of the caretaker which contributes towards help seeking and presentation for treatment (Swartz & Miller, 1992). Swartz & Miller (1992) give details of the calibration of the instrument in the Western Cape.

### **2.2 PARTICIPANTS**

Of the 203 residents who presented for treatment during this week, 170 agreed to participate in the broader study. These patients filled in self report forms, which included identifying data, five questions investigating possible depression, and the General Health Questionnaire, which is designed to identify people who are likely to be psychologically distressed, or to be suffering from a current, diagnosable disorder (Swartz & Miller, 1992).

Every fifth person presenting at each of the different sites of primary health care provision in the larger survey was selected for the portion of the study reported in the current dissertation. The number of participants selected for this study, therefore, is not one fifth of the total sample. This process resulted in 32 patients, 12 men and 21 women, being selected for interviews. In addition, it was decided, for ethical reasons, to follow up any patients designated as probable "cases" according to the GHQ, who had not been identified as such by the primary health care practitioners. On this basis, one patient (a woman) was added to the study. The inclusion of this patient, designated as a probable "case", is likely to have biased the sample in the direction of psychiatric symptomatology. It may be predicted, for example, that this patient would suffer from nerves.

Of the 32 patients selected, 27 consented to an interview. Three men and two women refused to be interviewed. In addition, five patients, three men and two women, were not available to be interviewed within ten days of their consulting the doctor, and it was decided to exclude them from the study. Three of these patients, two men and one woman, agreed to be interviewed during the weekend, but were not at home at the arranged time. A further patient who had agreed to be interviewed (a woman) was a shift worker, and could not be contacted to arrange a time for an interview. The last of these patients, a man, was visited several times, but was consistently under the influence of alcohol and was not interviewable. The unavailability and refusals of these patients (six men and four women) resulted in an under-representation of men in the sample. The effect of the exclusion of these ten patients on the nature and external validity of the data will be discussed later in the study.

Due to time constraints, two of the participants were interviewed by a second researcher, and were not included in this study. Data from one of these interviews has been written up elsewhere (see Swartz & Miller, 1991). The participants in this study, therefore, number 21.

### **2.3 INTERVIEWS**

An interview schedule (see Appendix) was developed by the research team, consisting mainly of open-ended questions, which covered five areas.

The first section dealt with basic demographic data, including questions concerning the patient's involvement in the original baseline study in 1985 - 6 (Katzellenbogen, Joubert, Hoffman & Thomas, 1988), and disability.

The second section focussed on the visit to the doctor, and their understanding of their illness at this point in time. This section was based on questions developed by Kleinman (1980, pp.104 - 118) for eliciting the details of explanatory models of illness. The questions elicited the patients' identification of and label(s) for their illness; the nature of the pathology; the aetiology and timing and mode of onset; the course and severity of illness; their perceptions of the treatment they received; ideas about prognosis; and lastly, a brief outline of their lifeworld and personal and family illness history.

The third section of the interview investigated ideas about possible improvements in health care. The questions covered suggestions for improvements in care, their feelings about the amount of time available to speak to the health care provider, and issues of access and cost.

The following section dealt with patients' views on psychosomatic illness and nerves. This section elicited patients' ideas about the aetiology of illness generally, and the relationship of illness to social, economic and psychological factors; their ideas about and experiences of nerves, and about mental illness.

The final section was not part of the interview as such, but required the interviewer to note impressions of the home, the patient and the family, and where appropriate, to include brief details regarding the mental state of the patient and a possible diagnosis.

## **2.4 PROCEDURE OF DATA COLLECTION**

Patients who had been selected for the study were approached by researchers in the waiting room after their consultation with the doctor, and the study was introduced to them. Once consent had been obtained, an appointment was made for the patients to be interviewed in their own homes, within the following ten days. Kleinman (1980, p.106) suggests that explanatory models are more easily elicited and more accurately reported in the patient's home, by a researcher who is not associated with the delivery of medical care. The patients were therefore interviewed in their own homes by a researcher who had not been involved in the initial selection process. The interviews began with an explanation about the aims of the project, the position of the researcher as associated with the Mamre Community Health Project, and the assurance of confidentiality. The length of the interviews ranged from one hour to one and a half hours. The majority of the interviews were conducted in Afrikaans, which is the home language of the majority of the participants, or a mixture of Afrikaans and English. All participants insisted that they were able to speak and understand both languages equally well, but were encouraged to use the language in which they felt most comfortable. Written notes were taken and the interviews were tape recorded. This ensured accurate recall of the interview material, and as a result of the tape recording, allowed the interviewer to devote full attention to the participants at appropriate points in the interview.

## **2.5 METHOD OF ANALYSIS**

The material was analysed using a combination of quantitative and qualitative methodologies. The quantitative analysis provided indications of the frequency of types of illness and patient responses to illness and treatment. The qualitative analysis drew on Kleinman's (1980) explanatory model framework, with the aim of understanding the particular experience of

each participant. A qualitative approach is described as the most appropriate method for the study of beliefs about the origin, meaning, social significance, prognosis and appropriate treatment of illness (Kleinman et al., 1978; Kleinman, 1986; Helman, 1991). The data may be interpreted using analytical concepts, frameworks and research findings developed in medical anthropology (Kleinman, 1986).

It is acknowledged, in relation to these interviews, that "narratives that occur in the context of interviews, no matter how open-ended and lengthy, are co-authored enterprises" (Williams, 1984, p.181, cited in Lang, 1989, p.308). Thus the participants' accounts will have been affected by the demands of the interview and their perceptions of what is relevant and appropriate. The position of the researcher as a white woman and an outsider, would influence their perceptions of the requirements of the interview and the power dynamics of the situation. This was acknowledged by the researcher by indicating non-involvement with the health care system, by the use of clinical interviewing skills, and attempting to listen empathically and sensitively to the patients' accounts.

In addition, the idea that "the patients' explanations [of illness] are dynamic entities, constantly readjusted and modified" (Hunt, Jordan, and Irwin, 1989, p.955) is acknowledged; the particular understandings described at the time of the interview may have changed since the first perception of the illness, and are affected in an ongoing way by the doctor's response, as well as the responses of those in the patient's social environment. Despite the possibility that "retrospective narratisation" (Kleinman, 1988b, p.50) may have resulted in some reworking or distortion of the events of the illness experience, given the approach of this study, this does not affect the value or significance of the material.

In the following section the illness accounts and explanatory models of the patients are presented, in terms of the different sections of the interview, as outlined earlier. The names of the participants have been excluded for reasons of confidentiality. The aim of this study is to focus on the patients' perspectives by presenting their understanding of the experience, in the original language, or mixture of languages, in which it was reported. Translation has not been attempted as it was felt that this would result in the distortion or loss of meaning. Given the amount and range of data collected in the interviews, certain aspects have been selectively reported, specifically, individual details of the nature of symptoms and pathology, and course of illness. For reasons of space and to avoid repetition, discussion of findings has to a large extent been integrated in the reporting of the findings.

**FINDINGS**

The findings of this study are presented in four sections. Firstly, identifying characteristics of the patients and their families, including basic details concerning the demographic and financial composition of their households, are outlined. Secondly, the patients' explanatory models of the illness are discussed, in terms of (a) identification of their illness; (b) their understanding of aetiology; (c) the effect of the illness and their assumption of the sick rôle on their social environment; and (d) their experience and perception of treatment. The third section is concerned with their understanding and experience of psychosomatic illness and nerves, and ideas about mental illness. Finally, the results are concluded with an account of one patient's illness narrative, presented as an illustration in the form of a case study.

**Table 2. Identifying and Demographic Characteristics**

<b>Age</b>	
Range	18 - 75
Mean	39.6
<b>Gender</b>	
Male	16
Female	5
<b>Education</b>	
Range	0 - Std.10
Median	Std. 6
<b>Employment</b>	
Full-time	7
Part-time	1
Unemployed	9
Students	1
Grant (disability)	3
<b>Household Composition</b> (Per household)	
Mean number	6.4
Adults	4.5
Children	1.9
Median	6
Mode	4
Range	2 - 19
<b>Employed people</b> (Per household)	
Mean	2.05
Median	2
Mode	3
Range	0 - 4

**3.1 IDENTIFYING AND DEMOGRAPHIC CHARACTERISTICS**

The identifying and demographic characteristics of the participants are represented in Table 2.

In two of the three households which received grants, no household member had regular employment. One of these households consisted of two elderly women who supported themselves on the patient's grant and her sister's pension. The other household, which consisted of a couple and two children, received financial assistance from adult children who live and work in Cape Town.

The gender distribution of 16:5 women:men participants is noteworthy. In the broader study, 55% of respondents were women and 45% men. For this to be reflected in the figures for the current sample, the expected ratio would be 11,55:9,45 women:men.

A chi square goodness of fit test using a correction for continuity, because there is 1 degree of freedom, (Roscoe, 1969, p.190) for the observed proportion yields the following:

$$\text{chi squared (observed)} = 3,00$$

$$\text{chi squared (expected at the .05 level; 1df)} = 3,84$$

Since the observed chi squared statistic is less than the critical value, the null hypothesis that the proportion of women to men accurately reflects the larger sample proportion must be accepted on statistical grounds. Nevertheless, the response pattern by gender is interesting on clinical grounds; this will be discussed in the following chapter.

### 3.2 EXPLANATORY MODELS

As 21 patients were interviewed, figures here refer to frequencies from a total of 21.

#### 3.2.1 Identification of their Illness

All the patients were able to provide diagnostic labels for theirs (n=19) or their children's (n=2) illnesses. These are represented in Table 3 below.

**Table 3. Diagnostic Labels for the Illnesses**

Illness	Men	Patients Women	Children	Total
<b>Chronic Illnesses</b>				
'High blood'	0	5	0	5
Backpain	3	2	0	5
Angina	0	1	0	1
Athritia	0	1	0	1
Asthma	1	0	0	1
Eczema	0	0	1	1
Epilepey	1	0	0	1
Diabetes	0	1	0	1
'Maag Senuwees'	0	1	0	1
'Bene wat lam is'	1	0	0	1
<b>Acute Illnesses</b>				
Bronchitis	0	1	2	3
'Cold and Flu'	0	1	1	2
Earache	0	1	0	1
Chest Pain	0	1	0	1
Shoulder Pain	1	0	0	1
'Gastro'	0	1	0	1
Bladder Infection	0	1	0	1

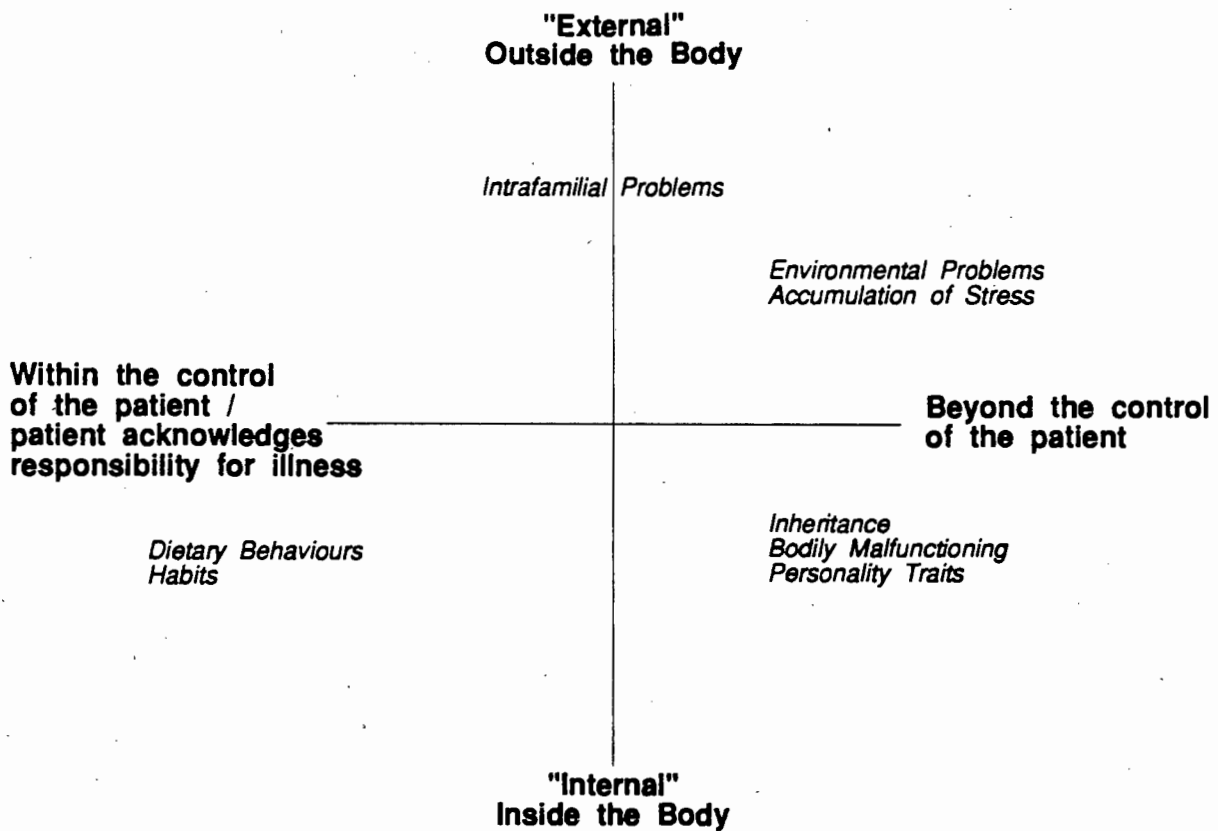
Broadly speaking, the illnesses reported by the patients may be divided into two groups; those which may be labelled "chronic", and those which may be labelled "acute". These labels are based on the idea that some people reported consulting the doctor on a regular basis, for treatment of what was perceived by them as an ongoing illness, whereas others perceived their illness as of short duration, and did not foresee themselves returning to the doctor in the near future.

The "chronic" group consisted of five reports of "high blood" (all women); five reports of "backpain", and one report of each of the following - "angina", "arthritis", "asthma", "eczema", "epilepsy", "maag senuwees", diabetes ("suiker probleem") and "bene wat lam is". Within this group, however, some patients reported suffering from more than one "chronic" illness, or an "acute" illness in addition to the continuing "chronic" illness. For example, on this occasion No 6 consulted the doctor about his asthma, but he also suffers from backpain - " 'n rugkwaal"; No 18 suffers from arthritis and "high blood", but on this occasion she consulted the doctor on account of what she termed "gastro". The number of illnesses reported will not therefore correspond with n=21. In fact, although only eight patients reported consulting the doctor on this occasion for "chronic" illnesses, the interviews revealed an additional three patients experiencing "chronic" complaints, and amongst these eleven patients, 18 different "chronic" disorders were reported (four men and seven women). Significant commonalities within gender were that "high blood" was confined to women, whereas three of the four patients who were disabled by their illness to the extent of being unable to work, were men.

The illnesses which may be labelled "acute" consisted of three reports of "bronchitis", two reports of "cold and 'flu", one report each of "earache", "chest pain", "shoulder pain" (sports injury), "gastro" and a bladder infection ("blaas probleem"). Of the eight adult patients reporting "acute" illnesses, seven were women.

### **3.2.2 Ideas about and Understanding of Aetiology**

The patients' ideas about the aetiology of their illness may be defined relative to two axes, as depicted in Figure 1 - the first being "outside", or psycho-social causes, versus "inside" or physical causes; the second being causes for which they feel responsible, versus those which are beyond their control.



**Figure 1: Ideas about and understanding of aetiology**

Psycho-social causes included ideas relating to intrafamilial issues, employment and environmental conditions, and what may be termed the "accumulation of stress of normal living" (Blumhagen, 1982). Physical causes, on the other hand, included ideas about bodily malfunctioning, the inheritance of the illness from a family member, and "personality traits" which are understood to affect health. The acknowledgement of personal responsibility included the feeling of having done something (smoking, drinking, getting cold and wet) which had caused or contributed to their illness. Generally, however, patients perceived the aetiology of their illnesses as beyond their control. Intrafamilial problems appeared to be an exception to this in some cases. This differed according to their circumstances; some patients felt unable to effect any changes in their situation, whereas others had or intended to take action to bring about changes (an example of this would be No 2 who had left a conflictual marital relationship which she felt had adversely affected her children).

In all cases, patients suggested more than one aetiological factor in the constitution of their explanatory model. Patients tended to describe their aetiology in terms of a cluster of factors, which were loosely linked, unrelated or apparently contradictory. These may include ideas gathered from different health care systems, the popular, folk and professional health care

systems (Kleinman, 1980). An example of this may be No 6. He developed "kort asem" and experienced feelings of weakness and tiredness. His uncle suggested that he had asthma, an illness "inherited" from the father, who died when the patient was two years old. The patient feels that he, rather than any of his siblings, was afflicted with this illness on account of his smoking and drinking. He believes it has been exacerbated by the stress of work and the air in Mamre. He feels that if he takes good care of himself, the asthma may "go away".

Psycho-social issues, specifically intrafamilial (n=8) and environmental problems (n=8), were the most commonly attributed aetiological factors. Intrafamilial conflict and tension were reported as contributing to illnesses such as "high blood" (n=3) and "eczema" (n=1). For example, No 1 reports that "laas week by Suster Mercy [the community health worker] sy't gesê my bloed is op ... ek dink dis die ontsteltheid oor die naweek, die groot kinders en die drank-probleme wat hulle het". Another example would be No 2, who felt that her child's eczema was exacerbated by her having witnessed physical abuse of her mother by her father - "Sy dink baie daaraan".

Environmental issues contributing to illness included the weather - No 5 gets a backpain when the weather changes; No 6's asthma is exacerbated by the air in Mamre - "Die lug is te stowwerig by Mamre". Secondly, unsatisfactory living conditions were cited - No 13 feels that her children's bronchitis was caused by "die koue in die huis; as jy die stoof aansit, dan is die hele kamer nat, en die nattigheid bly mos binne. En daar is ook te veel asems in die huis".

In some cases it is difficult to separate intrafamilial and environmental attributions; for example, when women in their rôle as mothers attributed their illness to environmental issues, rather than to the performance of a task which is perceived as part of their rôle and responsibility within the family network. Examples of this are No 12 who complained of obesity, saying "dis 'n vrou se probleem, om met kos te werk", or No 3, who suffers from high blood and angina, who reports "They depend on me. I had to do everything - when I came from work on the weekends, I had to look after my brother and his sons who were in the house", or No 16, who reports that she got "natgerënd" when she went out to fetch the washing from the line. Similarly, men who attributed their illness to stresses at work, or "inherited" illness, appeared to experience considerable anxiety in relation to their rôle as provider for the family. For example, No 6 reports that despite experiencing a range of symptoms - "kort asem, en ek was soggens so moeg en so swak" - he resisted going to the

doctor because he was "eintlik bekommered, want die kinders was nog op skool, en die jongste was net 'n baba".

Inheritance was cited as a contributing factor in the aetiology of the illness in six cases. This was in some cases reported as part of the doctor's explanatory model which appears to have been integrated into that of the patient. For example, No 15, who was diagnosed as having a "sugar problem", reports that the doctor enquired about "familie probleme met suiker, en amper al ons mense het die kwaal"; she accepts that as the reason for her illness. In other cases, the inheritance of an illness was suggested by family members, for example No 14, who suffers from "backpain". His brother and his sister also have backpain, and his mother feels that the children have inherited this from her.

Ideas about bodily malfunctioning were also suggested by some patients. In some cases these were based on explanations reportedly given by the doctor, in others patients had developed their own understanding. No 4 attributes her bladder infection to her discontinuing the contraceptive injection, and she explains "ek dink die injection moet tyd hê om uit te werk ... en iets het verkeerd gegaan". No 6 reports that the doctors explained his back pain as a result of his having four bones instead of three, and the fourth bone is growing "in my senuwees in".

The idea that certain behaviours for which they were personally responsible had exacerbated the illness was also evident (n=4). Both No 1 and No 18 incorporated the doctor's explanation of their "high blood" and "maagpyn", attributing it to the "fatty" food they ate. Despite this knowledge, however, neither of these patients had changed their dietary behaviours. Chest complaints were linked to smoking (No 6 and No 13), and No 6 reports having given up smoking when his chest problem was diagnosed as asthma.

Other aetiological factors suggested included the idea that specific personality traits, for which one was not responsible, were the cause of their illness. No 9 attributes her "high blood" to her "senuweeagtigheid": "Ek is van kinderdae senuweeagtig, ek het gehakkel".

The idea of an accumulation of stress, to which one was bound to succumb at a certain point, or a predetermined capacity for stress, which, when reached, resulted in illness, was suggested by one patient in her comment that "'n mens moet maar siek word, ek het nie vir 'n lang tyd siek geword nie".

Some patients mentioned specific ideas or fears they had had prior to going to the doctor. For some patients (n=2) these ideas related to illnesses suffered by parents or relatives who had recently died.

### 3.3 LAY THEORIES OF ILLNESS

Patients' ideas and beliefs regarding the aetiology of illness generally, as opposed to models of their own disorders, were investigated by eliciting explanations of the relationship between psychological, social and economic factors and illness.

As described by Helman (1990) with regard to psychosomatic disorders, most of these patients' theories and beliefs about illness involved multi-causal explanations. There were examples of illness attributions to the individual patient, the natural world, and the social world (see Helman, 1990). As with the discussion regarding the aetiological explanations of their own disorders, the patients' ideas about illness will be categorised primarily according to the extent to which they were perceived as "external" or "internal", and beyond the control of the patient or within the patients' control.

The majority of patients (n=16) believed that illness was affected, and in some circumstances caused, by economic and social problems. This was described in terms of living with conditions of material deprivation or stress such as homelessness, unemployment or poverty. Related to this was the idea of exhaustion or overwork (n=3); "as jy te veel werk, moeg kry, die moegheid laat jou siek voel". In addition, many of these patients (n=9) felt that difficult or disruptive experiences in relationships at home or at work could also contribute to the onset of illness. According to these patients, people get sick as a result of struggling or having problems - which is described as "swaarkry". "Natuurlik is mense meer geneig om siek te word as daar probleme in hulle lewens is ... Swaarkry maak 'n mens siek, dis soos 'n bekommernis ...". For some patients the process by which illness occurred was explained in terms of nerves: having problems was associated with nerves, which in turn contributed to bodily symptoms.

Some patients (n=2), however, qualified their explanation of the relationship between problems and illness; rather than a direct connection from problems to illness, they inserted the relative weakness or strength of "the body". No 8 feels that "dit hang mos af aan jou liggaam gesondheid". No 20 feels that the extent to which illness was caused by social, economic and psychological factors depended on the individual: "dit hang van die persoon af, hoe hy dit opneem ... Dit is as jou liggaam nie iets kan dra nie. Siekte het meer te doen met

'n mens se liggaam, as in die kop". No 12 explains: "As 'n mens probleme het, kry jy 'n hart aanval, of asthma attacks, of wat ook al jy het". This may be understood as the physical or somatic aspect, which included a predisposition to certain illnesses, which was understood as having a hereditary or constitutional basis, and may also therefore be perceived as being beyond the control of the patient.

The natural environment was also implicated as a possible causal factor in the onset of illness - the weather (n=4) "die natheid", die "koue", "die lug"; and elements within the environment, such as "kieme".

One patient (No 10) reports that illness had nothing to do with social, economic, psychological or environmental factors, but feels that "dit is die Here se werk".

These beliefs, which suggest that illness is generally beyond the control of the individual, were contradicted by the idea of a certain degree of personal responsibility for bodily health. For example, some patients (n=6) feel that a vulnerability to illness arises as a result of personal neglect: "if you don't look after your health, if you neglect yourself" (No 3). Related to this was the idea of unhealthy habits, such as "ongesond eet" (n=7), "drank" (n=4), "rook" (n=3), and "morsigheid" (n=1).

The idea of psychogenicity suggested by Helman (1990) was not raised by these patients; this may be a function of the cognitive categories through which patients and practitioners are interpreting the illness, which, as Helman (1988) points out, are derived from the social milieu.

### **3.4 THE EFFECT OF ILLNESS ON THE SOCIAL ENVIRONMENT**

On account of the general nature of the sample and the wide variety of symptoms and illnesses reported by those presenting for treatment, the course of the illnesses and the associated pathology varied widely. The focus of this section therefore is on the severity of the illness and the function and effect of the illness within the individual's daily life and relationships.

#### **3.4.1 Severity of Illness**

More than half the patients (n=13) describe their illnesses as "nie erg nie" or "not serious". However, four of these patients report that prior to going to the doctor they were concerned

that they (or their child) were suffering from a potentially fatal illness (for example, cancer, which had recently resulted in the death of a relative). Furthermore, three of the patients who describe their illness as "not serious" also state that they would have died had they not consulted the doctor. Six patients feel that their illness would have become more serious if they had not gone to the doctor when they did. It seems that, apart from differing definitions of "serious", the doctor's opinion regarding the severity of their illness affected and generally changed their opinion, and they felt that some aspect of the doctor's visit had ensured their survival or wellbeing. No 9, for example, explains that her illness was "not serious, as long as I do what the doctor says and take my pills regularly".

Of the patients who feel that their illnesses were serious (n=6), two based this on their perception that the illness had persisted for a long time (more than a year); while two others based their belief on their understanding of what the doctor had told them. No 2 feels that her child's illness was serious because "hy het net gehuil, en wil niks eet nie"; and one describes her illness as severe on the basis that she feels that her symptoms were similar to what she had previously experienced, prior to developing bronchitis.

One patient reports that she didn't know how serious her illness was and planned to ask the doctor. Another, who suffered from "gastro, high blood and arthritis", reported that her illness was "sometimes serious and sometimes not so serious". She felt that "no-one knows how long it would go on for. The doctor doesn't know."

### **3.4.2 Social Significance and Use of Illness**

Based on the patients' explanations, there appear to be both losses and gains involved in the process of becoming ill and assuming a sick rôle. In this respect, there appeared to be a difference between the problems caused by the illnesses of the "chronic" and the "acute" patients. In the explanatory models of the chronic patients, the most consistent underlying theme was the experience of loss. Most important, it seems, was the experience of loss of health, the sense of themselves as living in a healthy, reliably functioning body. They experienced themselves as different, a change to which they adapted with difficulty. No 3 explains "It's not nice to be sick when you were healthy. I wasn't so happy to stop working, but it was worse to be sick. It was very hard for me ... you know, when you are always on the go ... I had to change. I got very miserable about this". Another patient (No 6) reports that before his illness, he was "a very busy sort of person, I liked doing things, now I can't". Another

patient, a twenty-one-year-old man who had been laid off work on account of back trouble, (No 14) reports "Dit sal nou altyd daar wees".

Related to this experience of the loss of a normal, healthy functioning self, some patients describe constant anxiety about a recurrence or relapse. For some patients this may be quite extreme, for example No 5, who suffers from epileptic seizures, where he experiences complete loss of consciousness, and thereafter, confusion and disorientation. Almost as extreme is No 6, who suffers from asthma and reports that he feels uncertain as to whether he will be able to draw his next breath.

Another aspect of the experience of loss described by some patients (n=3) is the loss of independence, the inability to care for oneself. No 10, who suffers from "bene wat lam is" as a result of several accidents, reports that "my bene word lammer en lammer ... ek kan nie loop, nie ... ek kan self niks doen nie, ek wil iets doen, maar ek kan nie". No 6 describes a similar experience: "Toe kan ek niks vir myself doen nie; dis amper soos my bors toesluit".

For many of these patients (n=6) the inability to continue working, or the possibility of being laid off was experienced as a further loss. No 3 explains: "I was still in my early forties - at that time you want to work and go on". No 5 reports losing his job when the epilepsy was diagnosed. Although he receives a disability grant, he experiences constant financial problems. Some patients, however, did not emphasise this issue. This may be attributed to a range of possible reasons: it was not specifically elicited; the disability grant was as much as they had been earning; they had on some level accepted their sick rôle; and their illness experience was in some way more profitable for them than their earning capacity.

The experience of loss was reported mainly by patients who had suffered from a chronic condition for more than five years. In most of these cases it was difficult to unravel the circumstances surrounding their becoming ill, or to ascertain the existence or rôle of external stressors in their becoming ill, although one patient reported feeling very anxious about his financial responsibility towards his family. It is worth noting that the four patients suffering from "chronic" conditions which prevented them from formal, full-time employment were, at the time of their becoming ill, all financially responsible for their family's maintenance. Three of these patients were men, and the woman was responsible for her niece who had been abandoned. It is possible that this was a stressful situation for them.

By contrast with the "chronic" patients, most of the "acute" patients (n=6) felt that their illness had not caused problems for them. One patient felt that it was a problem that she did not go to work on account of her illness.

In the case of the acute patients, the antecedent events were more easily remembered. In fact, most patients (n=8) reported experiencing some distress prior to becoming ill. For some patients, these were ongoing problems, aspects of their family life, and in most cases aspects for which it appeared that they felt they bore the burden of responsibility. An example of this is No 8, who reports that her twenty-three year old epileptic son "is 'n bekommernis vir my; ek moet hom dophou, en ek kan hom nie alleen laat uitgaan nie". She feels responsible for him despite the fact that she is sporadically employed. She does not question the fact that her husband, who is not employed, receives a disability grant, is at home much of the time, and does not share the responsibility for his son's care.

Others (n=4) were able to report a specific occurrence, from a week to six months prior to their becoming ill, which was experienced as distressing or traumatic. For example, a family fight (No 1), or the loss of a parent (No 12 and No 20). For these patients, then, aside from any problems their illness may have caused for them, problems appear to have contributed to their illness. In some cases the illness functioned as a catalyst to change the situation, if only for a while, or to provide some relief from the ongoing stress. For example, No 1 understands that her illness is related to family problems. She explained this to her family in an attempt to bring about some change in their behaviour, in order that "ek meer kalmte kan kry". The family then promised to behave differently.

Many of the women, who are responsible for maintaining and organising for the needs of the household, expressed some concern about not being able to fulfil their "duties" as a result of their illness, but were also fairly confident about their families' ability to cope with what needed to be done - for a few days at least. Thus in cases of acute illness, the assumption of a sick rôle by the patient resulted in a shift in the accepted rôles amongst other family members (n=7). For example, No 16 reports that she can't afford to get sick, as there is no-one else to look after "die kleinkind" (her grandchild) or do the housework. However, if she is *really* sick, then her husband helps with the cooking, and her daughter stays at home to look after her child: "Sy moet ook sukkel met die kinders" says No 16.

In their explanations of their illnesses, some patients used what they reported to be the doctor's diagnosis to name their illness, to the extent of (n=9) using the words: "Die dokter het gesê ...", suggesting the incorporation of this diagnosis into their explanatory model. In addition, five other patients, in the course of their narratives, appeared to have integrated aspects of the doctor's explanatory model into their illness understanding. Three of these patients reported having a specific idea (or fear) as to the nature of their illness prior to their visit to the doctor, and that this idea changed as a result of the doctor's diagnosis. For example, No 1 feared that her stomach ache might be a symptom of cancer, and No 20 felt that her chest pain was a symptom of heart problems. The doctor's diagnosis was reported as "maag senuwees" and "iets met die slukderm" respectively. In the light of the work of Hunt, Jordan et al., (1989) who argue that fit with daily circumstances and interaction within the extra-medical social environment are of paramount importance in terms of integrating the diagnosis, it would be interesting to follow up whether these diagnoses were maintained. At this point, No 1 felt relieved and reassured by her diagnosis of "maag senuwees" and "high blood", and in fact was using it as a means of controlling behaviour in the family which had been the source of considerable distress to her. The diagnosis therefore appears to have legitimated her illness, and to have functioned within her social context as a "weapon of the weak" (Scott, 1985, cited by Scheper-Hughes, 1992). The patient explains: "Soms is ek nie in hulle oë reg nie ... Alles moet reg wees want die drank sê ek wil dit hê, ek wil dat hê ... Maar ek wil nie hê dat hulle baie vir my daarmee moeg maak nie ... ek voel dat my gesondheid daar gaan ... ek is die een wat gaan suffer".

In the case of No 20, the diagnosis of "iets met die slukderm" appears to have been ambivalently accepted. This is suggested in her use of language to report the doctor's diagnosis; "iets met die slukderm", as well as the fact that she reports that she will go to another doctor if the pain recurs. Her ambivalence may be understood in the light of the fact that she explains her fear of "heart problems" in terms of having cared for her parents who both suffered from heart problems. It is possible that her attribution of her symptoms to "her heart" may represent the possibility of receiving some kind of care or recognition and, in a sense, legitimate what she describes as the stresses of her rôle as caregiver to her parents.

### **3.5.2 Patient Satisfaction with Treatment**

There is a significant association (Fisher's exact probability = 0,0054) between the patients' report of incorporation or non-incorporation of the doctor's diagnosis and the extent of

satisfaction with the consultation and treatment. Of the fourteen patients who used the doctor's diagnosis as part of their explanatory model during the interview, thirteen reported being satisfied with the doctor's treatment, and one patient planned to return to the doctor to query a symptom which had appeared since starting the prescribed medication. Seven patients used their own terms in naming the illness, for example, that the baby suffered from "winderigheid", or described their sickness as "bene wat lam is". Of these seven patients who were more resistant to incorporating or accepting the doctor's diagnosis, five reported feeling dissatisfied with the consultation and treatment, for a range of reasons. Two patients, who reported "backpain" and "a torn muscle" respectively, felt that doctors could not help them; they needed physiotherapy. A third reported a "misdiagnosis": the doctor had diagnosed her daughter as suffering from scabies and prescribed some ointment which "het haar vel stukkend gebrand". The child had previously been diagnosed as suffering from eczema at Red Cross Hospital. The mother felt that the doctor was negligent in that he had not examined the child fully, had looked only at her hands.

An additional issue is that of changing doctors; two patients who felt satisfied with their present doctor reported that, within this illness episode, they felt dissatisfied with the first doctor they had consulted, and then consulted a second. No 7 reported that the first doctor he consulted had not given him any time off work, so he had consulted a second doctor on the same day, who provided a sick leave certificate. No 15 felt that the first doctor she consulted had been less than thorough; he had not examined her, had simply given her non-prescription ointment. By contrast, the second doctor had done a thorough examination, taken blood and urine samples, and had asked her questions, for example, whether there was a family history of "suiker probleme".

However, the tendency to report that they were "tevrede" (satisfied) with the treatment (n = 14) is possibly misleading, for several reasons. Firstly, their state of health at the time of the interview would affect their feelings retrospectively about the efficacy of the treatment. Secondly, their perception of the status and loyalties of the researcher may affect their responses, especially in cases where the researcher was called "dokter", despite explanations to the contrary. This apparent satisfaction appears at times to belie some misgivings about the actual treatment, especially in cases where patients did not experience the treatment as legitimating of their illness. For example, No 20 stated that she was satisfied with her treatment, but added that if the pain returned, she would go to another doctor. Similarly, No 17, who experienced recurrent backpain, which was on this occasion reportedly diagnosed as

"n spier of iets", stated that she was satisfied with the treatment, but later reported that if the doctor had taken "X-ray photos, the cause may be discovered ... and I may have to stop working". This, and her use of the word "iets" seems to suggest that she experienced her illness as possibly more serious than the doctor's diagnosis and treatment implied, and that she felt that it had not been properly investigated.

### **3.5.3 The Time Factor: Length of Consultation**

Reported satisfaction with treatment is also called into question in relation to the patients' feelings about the amount of time spent with the doctor. Twelve patients felt that they had enough time with the doctor. Five of these were patients who suffered from "chronic" illnesses, and felt that the doctor "knew" them, or remembered them from their previous visit. Of the twelve patients who felt that they had enough time to discuss their illness with the doctor, two had moved from other doctors as a result of what was perceived as inadequate care, and had chosen their present doctor partly on the basis of his receptivity, their perception that he was sympathetic to their illness experience in his manner of examination and treatment, and that he provided what was perceived as a proper or sufficient care.

Eight patients felt that they did not have enough time with the doctor; four of these were patients who also reported feeling dissatisfied with their treatment. One patient explained: "Hy was 'n bietjie hastig, hy het baie hande vol, baie mense. Ek wou hom verduidelik, maar ...". Another patient reported that she knows that the doctor comes from 2 - 5 p.m., that there are 40 - 50 people in the waiting room, and as a result "hy maak homself hastig met jou en jy kan nie uitpraat nie". This is experienced as problematic by some patients; as No 2 explained "n mens gaan om lekker met die dokter te gesels".

It would seem that this lack of time available to speak to the doctor may also affect the doctor's contribution to the patients' understanding of the aetiology of their illness (discussed previously in Understanding of Aetiology). In some cases (n=6) the aetiology of the illness was reportedly discussed during the consultation, and the doctor's suggestions about aetiology were incorporated into the patient's explanatory model. However, in the majority of cases (n=11) aetiology was not reported to have been discussed and patients' ideas about aetiology appeared to have been drawn from the popular and folk health care systems. It may be significant that in all the cases where aetiology was reported to have been discussed, patients reported feeling satisfied with treatment. The lack of discussion around aetiology appears to

have been a reason for dissatisfaction at times: No 17 reported that the doctor asked her lots of questions but did not tell her why she was experiencing pain.

As discussed previously, it is possible that some negotiation around aetiology may provide some legitimisation of the patient's experience of illness. For example, No 3, who reported feeling satisfied with her treatment, explained that on being given the diagnosis of angina, and being put off work, she asked the doctor "What's the meaning of this?" to which the doctor replied that she had been doing too much, and she needed a rest. This explanation appears to have been integrated into her explanatory model; she reports that at the time of onset of her illness, she was "in service" with a family who "used to entertain every night" and she was looking after an old lady.

#### **3.5.4 Nature of Treatment and Rôle of Medication**

The most commonly prescribed type of medication was "pills" (n=18). This appeared to be what was generally expected by the patients; No 18 stated that she expected to get pills - "want hy gee my gereeld pille as ek daar toe gaan". Some patients expressed confidence in the "pills" - for example, No 16 reported that "Dit het goed gedoen; die dokter het gesê dat hy sou vir my 'n goeie pil gee, en ek het beter gevoel". It appears that the prescribing of medication played a significant rôle in the patients' experience of legitimisation of their illness, in that it indicated the seriousness of the illness. An example of this is No 14 who consulted a doctor about a "klein puisie" on her foot. The doctor initially told her this was due to "germs" and gave her "Germolene" ointment to apply to the "puisie". She was dissatisfied with this, explaining that "jy kan dit by Clicks koop". (Germolene is a non-prescription ointment which can indeed be bought at supermarkets.) Additional treatment consisted of ointment (n=3), cough mixture (n=3), days off work (n=2), dietary recommendations (n=2), injection, physiotherapy, infra red lamp, and "panado" (analgesics) (n=1). These types of treatments tended to be mentioned secondarily to prescription medication, supporting the above point.

#### **3.5.5 Expectations of Treatment**

The majority of patients expected the doctor's treatment to "help" in some way (n=18), ranging from those who expected a full recovery (n=11) through those who saw the doctor as being able to provide some relief from their symptoms and/or pain. In addition, a minority felt the doctor could not help them. Comments therefore ranged from: "Ek het nie baie verwagtings gehad nie, ek het net geweet dat wat die dokter sal gee, dit sal help, dit sal alles

regmaak", to the less convinced: "I don't know my dear. Now I'm feeling alright. I don't feel any worse", to No 10 who did not go to the doctor when his legs became "lammer en lammer", as he felt that the doctor could not help. Fourteen of these eighteen patients reported that the treatment had helped to a greater or lesser extent.

### **3.6 USE OF ALTERNATIVE SOURCES OF CARE**

The question of patients' expectations of treatment may also be considered in relation to the extent to which they sought non-medical or alternative sources of help prior to or in conjunction with the prescribed treatment. Some patients (n=7) reported using non-allopathic medicines prior to seeing the doctor. These included herbal remedies (n=4) "blare in die veld wat my vrou van haar ma geleer het", household remedies (n=2) "olive oil on the brain" for headaches, "honey and eucalyptus oil" for chest complaints, and "kook water" for stomach complaints. They also reported consulting family members and friends for advice about their illness, for example No 2, who consulted her mother about her baby's "winderigheid" and "swollen naël". In most cases (n=6) patients tended to use these remedies and sources of help in conjunction with more conventional medical treatment.

### **3.7 SUGGESTIONS FOR IMPROVEMENTS IN CARE**

The most common suggestion for improvements in health care revolved around facilitating access to medical treatment (n=9). A variety of responses to this problem were articulated; to build a hospital in Mamre (n=4), the provision of an ambulance (n=5), the provision of more clinics and doctors (n=2), and that doctors should be available more often (n=2). Related to this were suggestions for the provision of additional facilities focussing on specific problems, for example, services for the treatment of alcohol-related problems (n=6), drug-related problems (n=1), tuberculosis (n=1), disabled people (n=1), the aged (n=1), and sports injuries (n=1). Three patients suggested that individuals should look after themselves better, and two of these patients added that one should also care for others. Two patients suggested environmental action to improve health care; that animals should be kept in demarcated areas, and that littering should be curbed. One patient suggested that "you should talk about the problem" (No 1). Finally, two patients responded that they "did not know" what possible improvements could be made to health care in Mamre.

The relative paucity of responses to the question of possible improvements in health care may stem from the day-to-day socioeconomic and political experiences of the Mamre community.

"hartseer"; No 9 feels that "dit laat jou verbouereerd voel, hastig in dinge wat jy doen"; while No 17 reports that "mense huil en raak so histeries".

Two patients expressed scepticism in relation to nerves. No 3 was reluctant to describe nerves, expressing her doubts about the existence of nerves. Eventually she explained that nerves were "worries". No 9, who described herself as "senuweeagtig gebore", reports that doctors say that there is no such thing as nerves: "'n mens moet die moeilikheid self oorkom". Both these patients were women over 65, which may indicate changing responses to stress and attitudes towards illness.

### **3.8.3 The Aetiology of Nerves: Explanations and Interpretations**

As with illness generally, the aetiology of nerves was linked to both "external" and "internal" factors - the "external" factors being social and economic stressors, which were seen as more significant. Internal factors may be described in terms of a predisposition to nerves, for example, that one was born "senuweeagtig". For both sets of factors, the responsibility for suffering from nerves was not located within the individual.

For some patients (n=15) "swaarkry" was linked to nerves: the emotional state associated with having "problems" is expressed as nerves. This seems to fit with Finkler's (1989, p.175) contention that "when individuals state they are experiencing nerves they are telling the world that they have embodied perceived misfortune and despair. Day-to-day perceived misery is experienced as worry and anxiety and is labeled as nerves". As No 2 explains: "as jy probleme het, is jy op jou senuwees". This was extended by some patients who felt that suffering from nerves could in turn lead to bodily illness. No 11 explains: "if a person has too many problems, they can make you worried, upset, sick, sonder eetlus en slaaploos". She uses the example of financial problems: "Dis op jou senuwees, want jy weet nie waar jy die inkomste gaan kry nie; dit affekteer jou liggaam - jy begin om minder te eet, jy verloor gewig, jy kan nie slaap nie - dan is dit makliker om siek te word". She concludes particularly graphically: "As jou senuwees op hol is dan affekteer dit jou liggaam ook".

Related to this was the connection between nerves and "worry". Worry was described as a response to having problems. As No 13 explains: "Nerves is veroorsaak deur probleme, dis 'n probleem siekte; (an illness caused by problems) jy voel asof die probleem veroorsaak by jou; dis jou fout dat hulle drink, dat hulle baklei". No 3 explains simply: "Nerves is worries".

This was extended by some patients who described nerves as an expression of feeling overwhelmed or out of control. No 11 describes nerves as: "n soort gevoel wat jy kry, dat niks sal reg kom nie, en jy's te swak om dit te hanteer". No 17 explains that: "jy kry 'n senuwee instorting as jou probleme te veel raak". No 14: "n mens kan dit nie meer vat nie - dis amper soos daar nie meer woorde is nie".

Nerves were also explained as an expression of "negative" emotions, such as anger and fear. No 14 explains "dis iets wat opkom, as 'n mens kwaad word en kan dit nie meer vat nie". No 16 reports that "dis nes jy bang is", while No 15 reports that her children suffer from nerves when they are "vreesbevange" as a result of violent and conflictual behaviour in the home. Engel (cited by Helman, 1988) notes how some socially "bad" emotions are reified by some individuals into external agents that somehow "cause" them to feel ill or unhappy. Helman (1988) hypothesizes that this may result in the shifting of the responsibility for aetiology onto the reified parts of the patient's "self".

Traumatic, unpredictable or unusual events or experiences were also described as precipitants of nerves. No 5 reports that he became "sick with worry" and was "op my senuwees" when his daughter ran away from home. No 20 explains "as iets buitengewoon gebeur, jy kan dit nie vat nie".

Some patients (n=2) reported that they were born with nerves. No 9, who described herself as "nervous", denies that she had a "problem" with her nerves; she was "senuweeagtig gebore" (born nervous). The doctor had told her that it was a "natural thing", and this was interpreted by the patient as meaning that there was no treatment or cure.

#### **3.8.4 People at Risk**

For the majority of patients (n=14) people with problems were most at risk for suffering from nerves. Some patients specified the type of problems most likely to result in nerves, which included family problems (n=4) and stress at work (n=4). Some patients (n=4) reported that people may be at risk for nerves as a result of a traumatic event, while others (n=3) explained that anyone - "enige mens" - could suffer from nerves. No 4, however, feels that only people "wat nie heeltemaal normaal is" suffer from nerves.

### **3.8.5 Treatment of Nerves**

The majority of patients (n=17) reported the most commonly prescribed treatment for nerves as pills - "pille", "tablette" or "kalmeeer pille". Some patients (n=8) mentioned consulting the doctor in conjunction with this. An injection (n=2), admission to hospital (n=1) and talking to the doctor or a suitably qualified professional (n=2) were also reported as treatment.

Patients' ideas about what they felt would be appropriate treatment for nerves differed from what they reported was generally offered. Only five patients felt that pills were an appropriate treatment. Six patients felt that the doctor should be consulted, and five patients felt that "talking" was the most appropriate treatment. No 13 reports from her personal experience that the doctor had encouraged her to speak to him; she explains the process: "... nou vertel jy van jousef. Toe kom hulle by die kwaal, toe kom die kwaal uit, sonder om self te sê ... dit was die regte terapie, om met iemand te praat wat verstaan het, wat saam met my voel, dis die meeste wat help". No 14 reports that "as jy die besigheid uit kan praat, voel jy beter". The idea of a rest and to "keep calm" was also suggested by some patients (n=4) as a remedy for nerves. Some patients expressed reservations about taking pills for nerves: No 12 reports that although she knew that pills were the right treatment, she would not take them, she would use home remedies. No 14 states that one could get addicted to pills, and for that reason they should be avoided. No 10 reports that one did not have to go to the doctor, but simply take some time off, and after about half an hour one would feel better.

### **3.8.6 Nerves and Mental Illness**

Patients were asked to explain who they felt was at risk for mental illness. This was interpreted into Afrikaans as "sielsiekte". Some patients (n=5) reported that they did not know. This may be a function of the terminology; possibly a more colloquial description (such as "mal"/mad) would have elicited some ideas. The most common explanation for mental illness was that it originated in the condition of nerves/"senuwees" (n= 8). No 1 reports: "Dis nou seker maar ook mense wat nou aan senuwees ly", and No 7 that: "Dieselfde mense as wat senuwees kry, kry sielsiekte". Some patients indicated that it was an extension or exacerbation of nerves. For example, No 12 reports that people who become mentally ill are people whose "senuwees gesnap het, of senuwee instorting kry, as jy weet nie wat jy doen of wat jy praat nie; jy verloor control". The experience of being overwhelmed by too many problems or worries was also cited as a cause of mental illness by some patients (n=5). Some patients (n=4) feel

that mental illness resulted from head injury. No 21 specifies that one is not born with mental illness; this occurs as a result of something that happens. She went on to give the example of her cousin who suffered a blow to the head. Three patients feel that mental illness resulted from some incident or trauma but did not specify the exact nature of the trauma. Two patients feel that one was at risk for mental illness as a result of being "too clever". No 17 explains: "as jy te slim is, as jy te veel studeer, werk jou mind te veel, dis mos alles deurmekaar". This may have some similarities to the syndrome of "brain fag" reported by Nigerian students, as described by Prince (1985). The idea of a predisposition to mental illness was also suggested. Some patients reported that you were born like that: No 2 feels that mental illness was inherited. No 3 feels that "drink and drugs" caused mental illness, while No 8 feels that "een wat nie bid nie, of nie glo daaraan, dat dit kan reggemaak nie" became mentally ill.

### **3.9 CASE STUDY**

The final section is an account of one patient's illness narrative, presented as an illustration in the form of a case study.

#### **3.9.1 Identifying data**

Elvira is a 53 year old married woman, living in Mamre. She has a Std 3 education, and has never worked outside of the home. She is a large, well-built, slightly overweight woman. She was initially rather anxious and reserved, avoided eye contact. She responded to some questions a little self consciously, looking down and giggling. Despite the explanation about the nature of the research and the status of the researcher, she sporadically addressed the researcher as "Dokter" or "Suster".

#### **3.9.2 Current household circumstances**

Elvira and her family live in one of the older houses in Mamre, which appears to have been added on to in a fairly random and ramshackle way over the years. She lives with her husband, five sons, two daughters, daughter-in-law and grandchildren. One of her sons is married with five children, and her daughters have five children between them. She would like her son and his family to move out, but they have struggled to find accommodation. Only her husband, who is an unskilled worker, and one of her sons are employed. Elvira is

responsible for looking after the children during the day and for housework, and comments that "as hulle inkom moet alles reg wees, anders is daar 'n probleem".

### **3.9.3 Details of visit to the doctor**

Elvira went to the doctor on account of her "maag wat so gewerk het" and "so gepyn het". According to Elvira, the doctor explained her stomach pain as an "infection", "dan is dit die maag senuwees wat die pyn gemaak het". He also suggested that she had eaten "swaar vleis", and that she didn't chew her food properly on account of having had her bottom teeth extracted. He advised her to "cook her food soft". She had also asked the doctor: "Hoekom kry ek so kopseer?" The doctor "het bloed geneem" and informed her that her "bloed was op".

### **3.9.4 Course and nature of illness**

Elvira's symptoms had started a week prior to her visit to the doctor. She woke up with a "vreeslike kopseer", she felt very tired, weak and "bewerig", and her legs felt lame. She lay on her bed for a day, on account of the lameness of her legs. Initially her stomach felt "dik", full and bloated, then the pain moved to the middle of her stomach, and she experienced "burning". Then her stomach became very sore, and was "working". She was unable to eat. Before going to the doctor, she had told her daughter of her pain and discomfort, and was given "wonderkroon" and boiling water to drink.

Prior to going to the doctor Elvira had worried that her stomach pain was similar to that experienced by her niece, who had stayed with them six months previously. Her niece had become ill with stomach pain, and then died of cancer. Elvira reports that this was "so skielik - twee weke by onse, 'n ander paar weke by die hospitaal, en toe gesterwe aan kanker". She experienced her illness similarly - "dit het so gou gekom, so gou gebeur". She reports that the loss of her niece made her "baie hartseer" but that while her niece was ill she "het nooit gepraat by ons nie".

### **3.9.5 Aetiology**

In retrospect, Elvira feels that her "high blood" problems were caused by "die onsteltheid oor die naweek, van die groot kinders, en die drankheid". She reports that she had wanted to escape the household situation: "ek voel soms ek wil uitgaan, wegkry van die probleme, die hastigheid in .... die huis". She reports that although she has been diagnosed as "high blood" before, she had not experienced this as a problem prior to the weekend when she became ill:

"het nooit sleg gevoel nie, dis nou net toe die kinders so begin met die drank probleme, jy kry so opgewerk daarvan". She feels responsible, as the "huisma" to "make everything right": "alles moet reg wees want die drank sê - ek wil dit hê, ek wil dat hê - ... soms is ek nie in hulle oe in reg nie ... Maar ek wil nou nie meer my moeg maak daarmee nie ... want ek voel dat my gesondheid dan gaan; ek is die een wat gaan suffer".

### **3.9.6 Treatment**

Elvira reports that her illness is "better" since going to the doctor and taking the pills which he gave her, "want die doctor se pille help baie goed". At present she takes "maag senuwee pille, pyn and kalm pille, en medisyne wat met die pille saamwerk". She feels she would like a tonic, to get her appetite back - at times she doesn't feel like eating for three days or so, only drinks boiling water. She reports that the most recently prescribed medication took four days "to work" and then the "lammigheid is weg", and she no longer gets headaches. She asked the doctor about her niece's illness, and he assured her it was not the same. She believes him because if it had been the same as her niece's "dit sou aangehou het". She is worried that her high blood pressure will bring this on again, but feels that she will be "gereeld met medisyne". She also plans to avoid fats and sugar - "soetigheid of vetterigheid" - because of her high blood problem, following Sister "Mercy's" advice. (Sister "Mercy" is the liaison worker for the Mamre Community Health Project).

### **3.9.7 Prognosis**

She feels that if she hadn't consulted the doctor she would still be lying in pain, and would have to stay in bed for a long time, "so afgemat het ek gevoel". She reports that without treatment "ek sal te grond gegaan het". She feels that if she doesn't go back to the doctor and take her medicine, it will recur, "want maag senuwees is nie iets wat weg gaan nie" - as jy huis toe kom en kry ontsteld, dan kry jy jou senuwees". She feels that she may need additional medicine for her senuwees.

### **3.9.8 Effect on family relationships**

She feels that her illness will have a positive effect on family relationships. She hopes that her family will attempt to deal with their drinking problems so that they won't affect her so much, so that she "kan meer kalmte kry". They know about her illness, and said that they would try

to be more considerate and drink less, but she acknowledges that when they've got friends, they drink. She comments: "daardie drink probleme, breek mos 'n huis op, man".

### **3.9.9 Illness history**

She has never had this or any other illness before, apart from the "high blood". Her husband also suffers from "high blood", but there are no other illnesses in the family.

### **3.9.10 Perception of treatment**

She would like to have spent more time with the doctor; she wanted him to explain more to her about her illness. She experienced him as a bit rushed - "'n bietjie hastig", she could see that he was busy - "hy het baie hande vol, daar's baie mense".

### **3.9.11 Patient's views on psychosomatic illness and nerves**

Elvira feels that people may become ill as a result of problems in their relationships, "as dinge tussen mekaar nie so goed gaan; byvoorbeeld, kinderlike verhoudings".

She feels that her stomach ailment was caused by nerves. Nerves are described as "vreeslike maagpyn", which occurs as a result of "ontsteltheid". The best treatment for nerves is to consult the doctor, to talk about the problem and to take medication.

### **3.9.12 Suggestions for improvements in Health Care**

Elvira feels that health care in Mamre could be improved if people looked after their health and went to the doctor for treatment when ill. She feels that patients need the opportunity to talk about "the problem" and to get treatment. She also suggested that health care should include some treatment for drinking problems. She feels that such things - drinking and the resultant arguments - make you weak.

In terms of what has been discussed above, the relatively high proportion of women who participated in this study (76,2%) may have biased the data in favour of a higher prevalence of psychiatric symptomatology and nerves.

While the reasons for the overt (n=5) and covert (n=5) refusals of the ten patients to be interviewed are not clear, it is possible that their unwillingness to talk may be an expression of dissatisfaction with the treatment they received. Their exclusion would therefore have biased the data in favour of a higher level of satisfaction with treatment. An additional explanation could be that these patients who refused to be interviewed were experiencing higher levels of stress, (which, according to patients' descriptions, may be expressed as nerves) and for this reason did not want to talk. In this case, the exclusion of these patients may have resulted in a lower prevalence of psychological distress or disorders (or nerves) reported in this study.

In summary, then, it is possible to speculate about whether the sample is biased towards a higher or lower prevalence of psychiatric symptomatology and nerves. The extent to which the sample is representative is not clear, however, and this needs to be borne in mind.

## **4.2 LIMITATIONS OF THE STUDY**

As discussed above, restrictions of time and the unavailability or refusal of ten subjects affected the sample size, which was limited to 21. Although this may affect the generalisability of the results, the qualitative material presented by the patients is, in the context of this study, believed to be more important than the quantitative analysis of the material. Furthermore, it is believed that with a focus on the contextual basis of illness meanings, an approach which emphasised generalisations would be inappropriate (Spiro & Swartz, 1990).

Restrictions of time also affected the length of interviews; the number of interviews scheduled for each particular day necessitated, at times, having to curtail the amount of time spent with some patients, and therefore the degree of depth and detail of material elicited from the patient.

Comparative information about doctors' and patients' ideas about aetiology and diagnosis were not incorporated. The perspective of the doctor, in terms of aetiology, diagnosis and clinical impressions, would have provided a useful comparative dimension to the material, in terms of providing information about the extent of discussion and possible negotiation of

explanatory models, and the relationship between professional and lay explanatory models. Although this was beyond the scope of the present study, it is felt that these aspects could be usefully explored in future research. Many practitioners were interviewed as part of the broader study, and useful information was elicited (See Reynolds & Swartz, in press).

While this study has provided additional perspectives regarding lay theories about illness, and about nerves, the fact that this information was provided by subjectively ill patients presenting for primary health care suggests that their ideas may differ from those of a "healthy" population. An investigation into lay theories of illness and nerves amongst the general population alongside a subjectively ill population may provide a useful comparison, and a different range of ideas.

Despite these limitations, it is hoped that this study will be useful as an exploratory enquiry, and that future research may be of a more extensive nature.

#### **4.3 THE CONTRIBUTION OF PSYCHOLOGICAL FACTORS TO PRESENTATION FOR PRIMARY HEALTH CARE**

- ✓ In the broader study (described previously) 45,28% of the sample scored above the G.H.Q. cut-off point, implying that almost half of the people presenting for primary health care are likely to have psychological problems (Miller, Swartz & Rumble, 1991). This is considerably higher than the WHO estimate of 20% (World Health Organisation, 1990). The qualitative data provided by this study provides some indication of the extent and nature of the contribution of psychological factors to presentation for primary health care.
- ✗ Firstly, the aetiological explanations of their illnesses given by the patients in this study suggest that **illness** is more commonly understood to originate in factors external to the body, specifically, **intrafamilial** problems (n=8) and living conditions (n=4). Their descriptions of aetiology describe problems in their lives rather than problems within their bodies, thus implicating troubled lives which underlie and result in bodies troubled by illness.
- ✓ Psychological factors are also implied in the high prevalence of nerves within this sample. Nerves was described in terms of "swaarkry" or "worries". The aetiology of nerves is linked to socioeconomic stressors and intrafamilial problems. Although nerves was not offered by any of these patients as the reason for presentation for primary health care, more than half

(n=13) of these patients reported experiencing nerves, which may therefore suggest the contribution of psychological factors in their presentation for primary care.

X The prevalence of chronic illness (n=11) also suggests the implication of psychological factors in the presentation for primary health care amongst these patients. The illness histories and explanations of these patients reveal ongoing difficulties ('swaarkry') in their day-to-day lives and relationships, in part created by their illnesses. While the role of psychological factors in the genesis of their illnesses is not clear, the effect of chronic illnesses on the doctor-patient relationship and the ensuing recurrent attempts by patients to receive appropriate and sympathetic treatment is well documented (Kleinman, 1988; Good, Brodwin, Good & Kleinman, 1992). Swartz & Miller (1991) suggest that chronic patients' repeated use of primary health care may be an expression of their frustration at not being heard, their illness experience not being taken seriously, and at not receiving sympathetic treatment.

#### **4.4 IMPLICATIONS FOR CLINICAL PRACTICE**

It has been argued that patients' understandings and explanations of illness are formulated and transformed in an ongoing way, in relation to personal factors and social contexts, as well as physiological processes (Kleinman, 1981; Hunt, Jordan, & Irwin, 1989). Kleinman (1980, 1988b) has stated that effective clinical practice depends on eliciting patient explanatory models and making the patient's and the family's narrative of the illness experience more central in the treatment; that care of illness needs to be integrated with the treatment of disease. Discrepancies in explanatory models of patients and practitioners and the failure to discuss and negotiate these differences may result in unsatisfactory or ineffectual interventions, or patient non-compliance with prescribed treatment. While the extent to which explanatory models were elicited and negotiated is not clear from this study, it is apparent that patients do have ideas about what constitutes an adequate consultation. The dominant theme expressed in patients' accounts of treatment was the question of legitimation of the illness experience by the doctors' responses. As Reynolds & Swartz (in press, p.14) have noted, patients perceive the practitioner as having "better knowledge, or knowledge of a more powerful kind than that of the patient". Based on patient reports for this study, it is hypothesized that there is an association between the following factors: the "fit" of the doctor's diagnosis with the patient's explanatory model, which is rooted in their social context and life circumstances; the experience of legitimation as a result of the negotiation of explanatory models and/or type of treatment; the likelihood of incorporation of the doctor's diagnosis into

the patient's explanatory model; and patient satisfaction with treatment. However, this would need to be more specifically investigated in further studies.

The aetiological explanations provided by the patients (discussed previously) tended to emphasize external factors (intrafamilial or environmental problems), which are generally not addressed within a narrow biomedical approach. The biomedical model has been criticised for attending insufficiently to patients' illness experiences and the personal and social contexts of illness, resulting in problems in patient care (Good & Good, 1980; Kleinman, 1980). The disparity between what these patients perceived as aetiological factors and the treatment they reported receiving suggests possible neglect of their experience of illness. This would need to be corroborated by more direct observations of the treatment process. Research into the construction of nerves in Mamre suggests that while some practitioners evidenced fairly sophisticated understandings of nerves, others did not (Reynolds & Swartz, in press). For example, one of the practitioners interviewed reported attempting to explain to patients the necessity of dealing with the underlying social problems masked by their suffering from nerves.

The quantitative results of this study reveal that within this sample of patients, almost half of the patients (n=8) reported consulting the doctor on this occasion for "chronic" complaints. While psychosocial and psychological factors are acknowledged as important influences on chronic illness, the result of this has at times been the attribution of the pain, or the illness, to "a malfunction of the mind rather than the body [which] implies that it is the sufferer who is to blame for both the pain and for the failure of the practitioner to achieve a cure" (Good, Brodwin, Good & Kleinman, 1992, p.104). However, chronic illness or ongoing pain is experienced as a whole: "Perception, experience and coping run into each other and are lived as a unified experience" (Good et al., 1992, p.8). As explained by Brodwin & Kleinman (1987, cited in Good et al., 1992, p.10) both the psychological and biomedical traditions tend to ignore how a patient's experience of pain "unites its bodily, psychological and social origins".

Although cure may not be possible in chronic illnesses, the role of the practitioner would be to limit disability as far as possible, by dealing with life problems caused by the disorder. Allowing the patient to describe his or her illness experience within the context of his or her life world and history, and the 'witnessing' of the patient's story is of therapeutic value in itself (Kleinman, 1988b).

X The method of understanding illness advocated by Kleinman (1980; 1988b) and used in this study may be constructively employed by practitioners to support and assist patients and their families to deal with illness as well as psychosocial and illness-related problems. Despite pressures of busy practices and large caseloads, it is suggested that more effective interventions and improved patient care may result. This process is not without problems, however. The question of negotiating illness models is complicated by the lack of clarity around how this is to be achieved, in the light of "culturally complex and shifting understandings of illness" (Reynolds & Swartz, in press). In addition, although psychological training and knowledge are useful in understanding patients' illness experiences, it is important to recognise that any approach which claims total understanding excludes the patients' perspective. As noted by Swartz & Miller (1991, p.9) "a totalising formulation which attributes complete explanatory and therapeutic power to a psychological perspective is as dangerously flawed as a reductionistic, mechanistic view of disease".

X In addition, Reynolds & Swartz (in press), note that clinical communication takes place within a context, and changes in this context are necessary in order to facilitate changes in the approaches of biomedically trained practitioners. They (in press, p.20) suggest that the education of practitioners in the "minutiae of [doctor-patient] interaction" and the use of informal community support networks may facilitate the treatment of conditions such as nerves.

The finding that patient use of medication at times reflected their explanatory models, rather than the biomedical understanding, has important implications for management of certain conditions. Some of the patients reporting a diagnosis of "high blood" explained that they only took medication when they experienced headaches or dizziness. Even where patients acknowledged that certain behaviours contributed to the onset of illness, such as eating fatty foods and "high blood", they did not necessarily change these behaviours. This is supported by Vinch's (1992) findings in a study of explanatory models of hypertensive patients in Mamre. Vinch (1992) reports a discordance between what patients perceived to be causative factors and how they reported managing their condition. One of the current interventions in Mamre is a hypertension intervention programme. This information would be useful to them in developing approaches to treatment.

In conclusion, this study has investigated aspects of illness and experiences of treatment amongst a sample of patients presenting for primary health care in Mamre. It has outlined a hermeneutically-oriented approach to understanding illness and health care. A selective review of the literature relating to psychological issues in primary health care has been presented. It is hoped that the focus of the research - the investigation of patients' explanatory models of illness and experiences of treatment - has provided additional perspectives in developing an understanding of the contribution of psychological factors in primary health care, and will be of use to the clinical psychologists and other community health personnel working in Mamre.

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**APPENDIX I**

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PROTOCOL

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date of interview:  
length of interview:  
language of interview:  
interviewer:

1. Introduction

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[- from Mamre Community Health Project (Merçia Arendse) and  
UCT Department of Psychology]  
Interested in improving health care in Mamre  
Interested in people's experience of illness

2. Background data

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Name:

age:

date of birth:

address (do you always live here?):

sex:

marital status:

relationship to I.P.(if approp.):

employed:

education:

members of household (immediate family, less closely related  
family, boarders, others):

number of employed people in the household:

participate in the original baseline study? (1985/6):

Baseline study questions: disability

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Housewife (no other work, not looking for work)

Have you a health problem that results in:

- a) an inability to do any housework?
  
- b) able to do housework but limited type or amount possible?
  
- c) able to do housework but unable to do other tasks that you would like to do?

What is the cause of this?

Pensioner (>65)

Have you a health problem that results in:

- a) an inability to care for yourself at all?
  
- b) able to care for yourself but limited type and amount possible?
  
- c) able to care for yourself but unable to do other things that you want to do?

What is the cause of this?

Other adults

Have you a health problem that results in:

- a) an inability to work at all?
  
- b) able to work but limited type and amount possible?

c) able to work but unable to do other things that you want to do?

What is the cause of this?

**Details of doctor visit**

I understand that you went to see the doctor last week. Please could you tell me about it.

*Fill in all details about the visit*

What was wrong, according to pt?

When did it start and how?

What did they do about it?

**Explanatory models**  
(read: Helman p 96)

*Note: under the bold headings below, the following questions must all be asked, or answered without having been asked.*

\* **Nature of pathology**

*What do you call your problem? What name does it have?  
What does your sickness do to you? How does it work?  
What has happened?*

**\* Aetiology**

*(Explanation of causes of problem both in terms of pathophysiology and in terms of reasons for the problem affecting the patient and not anyone else)*

*What do you think has caused your problem?*

*Why has it happened?*

*Why has it happened to you?*

\* **Timing and mode of onset of symptoms**

*How did you first know that something was wrong?  
Why do you think it started when it did?  
Why now?*

\* **Course and severity of illness**

*How severe is it? Will it have a short or long course?*

*What do you fear most about your sickness?*

*What are the chief problems your sickness has caused for you?*

*What will happen if you don't do anything about it?*

*How will it affect your relationships with family, friends, workmates, etc?*

**\* Treatment**

*Are you receiving any treatment apart from what has been mentioned before? What kinds of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?*

*Where have you gone for help so far, and where else should you go for help?*

*[Previous help-seeking (popular, folk, professional)*

*Delay in seeking treatment, and reasons*

*Expectations for treatment, experiences of it*

*Experience of prescribed medication, lifestyle or diet changes]*

**\* Prognosis**

*What will be the outcome? What will happen in the end?*

**Life-world and illness narrative**

Life-world of patient and symptoms. (Placing symptoms and help-seeking in personal and family context). Basic question: how do symptoms and help-seeking affect and relate to the person's family and social circumstances (includes work). Some family history necessary. *(Note: you may need to go on to a separate sheet here)*

**Stressors in the past three months (especially changes and exit events).**

Illness history

Illness history - has this happened before, other related illnesses, and family illnesses. Family myths around the condition.

Suggestions for improvements in care

If things could be improved, how could they be improved?

Do they feel that they have enough time to talk to doctors/nurses?

Access

Cost

Patient's views on psychosomatic illness and nerves

Do they think that illness is affected by social, psychological, and economic factors?

Why do people get sick? Do people get sick because of swaarkry / problems in their families/relationships?

If I were to ask you whether you've ever had problems with your nerves, what would you answer?

If yes:

Have you ever had treatment for your nerves? In the past year?

Have you ever been admitted anywhere for nervous problems?

Where?

Did your going to the doctor last week have anything to do with your nerves? Explain.

Do you know anyone else who suffers from nerves?

What is nerves?

Who gets it?

How is it treated?

How should it be treated?

Who becomes mentally ill?

How can we improve health care in general for people from Mamre?