AN "INSIDE STORY" - THE ILLNESS EXPERIENCE OF WOMEN WITH BREAST CANCER

SHIRLEY BERGER
B.A.(Honours)(UCT)

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

Department of Psychology
University of Cape Town
1990

ABSTRACT

This study explores the illness experiences of five women with breast cancer. The literature on psychosocial aspects of breast cancer among women is reviewed and limitations noted. A medical anthropological approach to the study of illness and health care is outlined. The importance of investigating women's own accounts and of recognising the social experience of illness and the dynamic nature of responses and understandings is asserted. Two interviews with each woman took place soon after medical diagnosis and follow-up interviews were conducted eight months later with four of the women. Concepts and insights from hermeneutically-oriented medical anthropology have been applied to the interview material. Arthur Kleinman's framework for interpreting 'illness narratives' is used to elucidate the layers of meaning in each woman's story. These include: the meaning of the symptoms, explanations of the disease, the cultural salience of cancer and the significance of the illness within personal and social contexts. The way in which the illness is understood, expressed and managed within the patterns of daily living is discussed. Contact with the professional health care system is one aspect of this process. The study suggests that this approach to understanding women's experiences of breast cancer is both theoretically valuable and clinically applicable. [illegible]

ACKNOWLEDGEMENTS

I should like to thank:

The five women who participated in this study for their openness and for sharing their experiences with me

Leslie Swartz, my supervisor, for his insights and guidance and the enthusiastic way in which these were offered

The staff of the Groote Schuur Hospital Breast Clinic, and especially Dr Anne Hacking, for their assistance during the period of interviewing

Charles and my friends for their interest, encouragement and support, and Rochelle for her valuable advice

Alan and Peta-Ann for introducing the research area and for initial useful discussions.

The Institute for Research Development of the Human Sciences Research Council (HSRC) provided financial assistance. Opinions expressed in this dissertation do not represent those of the HSRC or any other organisation.

TABLE OF CONTENTS

Overview of the study 1

Introduction 2

1. Illness, culture and health care 2
   1.1 Medical anthropology and models of illness 2
   1.2 Clinical interactions and settings 4
   1.3 Health care systems and help-seeking 6
   1.4 Images of disease 7
   1.5 Illness narratives and illness meanings - Kleinman's model 8
2. Breast cancer 10
   2.1 Epidemiology, risk factors and treatment 10
   2.2 Breast cancer in South Africa 11
   2.3 Psychosocial aspects of breast cancer 12
3. Aims of the study 19

Methodology 20

1. Participants 20
2. Interviews 21
3. Method of analysis 22

Findings and Discussion 23

1. Illness narratives 23
2. Cultural meanings of breast cancer 37

Conclusion 40

References i

Appendix x

OVERVIEW OF THE STUDY

The popular mythology of cancer renders it a frightening and threatening illness, evoking fantasies of a "disease that doesn't knock before it enters ... an illness experienced as a ruthless, secret invasion" (Sontag, 1977, p.5). The cultural meanings of cancer strongly influence the illness experience of the afflicted person. The illness is shaped by personal and social themes; it is made sense of, expressed and managed within the patterns and struggles of daily living. Medical anthropological concepts and models may be constructively used in an understanding of the illness experiences of women with breast cancer. This approach may elucidate aspects of the experience which are neglected in other writing on the psychosocial impact of breast cancer.

This dissertation presents the 'inside stories' of five women with breast cancer. An interpretive framework, specifically that outlined by Arthur Kleinman (1988b), is employed to analyse their illness narratives. It explores the layers of meaning within their illness experience: symptoms, explanations and understandings, personal and interpersonal worlds and the cultural significance of the disease.

The theoretical introduction of the dissertation consists of two sections. In the first I begin by outlining the approach and key concepts of hermeneutically-oriented medical anthropology and their application in clinical settings. I move on to a brief look at the area of help-seeking and health care, followed by a discussion of contemporary images of disease and of the ill person. Kleinman's framework for the analysis of illness narratives is then outlined. In the second section the focus turns to breast cancer. I provide background information on the disease and present a selective review of the literature on psychosocial aspects of breast cancer.

The narratives of the five women interviewed are presented and discussed. I shall attempt to show the value of the theoretical framework adopted in this dissertation for an analysis of women's experience of their illness. As part of the evaluation, the relevance of the approach for clinical practice is considered.

INTRODUCTION

1. Illness, culture and health care

1.1 Medical anthropology and models of illness

The social sciences can make a significant contribution to the study of health and illness, and to the practice of health care. Medical anthropology has developed as a distinct field within the discipline of anthropology since the 1960s, and particularly since the mid-1970s there has been a significant and growing exchange between social anthropology and the disciplines of medicine and psychiatry (discussed in Eisenberg & Kleinman, 1980; Kleinman, 1980; Kleinman et al, 1978; Littlewood, 1990). Clinically applied anthropology has evolved within medical anthropology to highlight the application of social science concepts to clinical activity. In so doing it attempts to clarify clinical issues, improve doctor-patient communication and resolve patient care problems (Chrisman & Maretzki, 1982; Good & Good, 1980; Helman, 1984; Kleinman, 1980). By emphasising the patient's[1] perspective of the illness and by examining the meaning of illness experience as well as analysing the hermeneutic nature of clinical interactions, more integrated and appropriate health care may be provided.

The conceptual distinction between 'disease' and 'illness' has been outlined, with disease being defined as the malfunctioning of biological and psychophysiological processes and illness as representing the social experience of disorder, the personal, interpersonal and cultural reactions to disease (Kleinman et al, 1978). The conceptualisation has been reframed more recently. "Illness refers to the patient's perception, experience, expression, and coping with symptoms, while disease refers to the way practitioners recast illness in terms of their theoretical models of pathology" (Kleinman, 1988a, p.7). The biomedical paradigm, the dominant medical system in developed and Third World countries, focuses on the diagnosis of somatic dysfunction and attempts to link symptoms with somatic disorder. Diseases are social constructions in that patients' illness complaints are translated into diagnosable disease categories; biological processes are categorised and interpreted (Eisenberg, 1977; Helman, 1984; Kleinman, 1978a). It is thus possible to have disease without illness (e.g., when tests reveal a tumour but the patient has not experienced symptoms) or illness without disease (complaints without a recognisable biological base, commonly labelled 'psychosomatic'). Many medical consultations and patient care problems are related to illness rather than disease, particularly in chronic disorders.

---

[1] I shall, at times, use the term 'patient' while acknowledging its general usage to denote a recipient of professional medical care, and the power relations implicated in this relationship. Use of the term in this dissertation is not intended to defocus from the ill person's own understandings and activities.

The advances and successes of medical technology and biomedical models in understanding and treating the pathophysiology of disease are undisputed. However the biomedical system has been criticised for its reductionism, its neglect of patients' illness experience (Eisenberg, 1977; Engel, 1977; McHugh & Vallis, 1986), and its general inability to understand and incorporate the personal and social context of sickness (Kleinman, 1980). The biopsychosocial model (Engel, 1977) has been offered to remedy some of the limitations of the biomedical model and to provide an holistic approach to illness and clinical care. Based on systems theory, it depicts biological, psychological and social factors as operating on different but interconnecting levels. It may be argued that this model has led to greater awareness of psychosocial issues in health care and to certain changes in medical practice. However the model has largely been 'coopted' by the biomedical system, which remains the dominant partner of the bio-psycho-social combination. The nature of the relationship between the various levels of analysis is not elucidated and indeed the conflict between the different paradigms is ignored (Armstrong, 1987). On a clinical level there tends to be compartmentalisation of professional practice with the psychiatrist, psychologist or social worker being required to address the psychosocial aspect (Miller & Swartz, 1990). Issues of power in the clinical encounter are also neglected. Medical knowledge and practices are historically and socially constructed; political and economic factors are therefore implicated in the continued dominance of the biomedical approach. The biopsychosocial model has not significantly challenged this dominance.

A hermeneutically-oriented medical anthropological approach attempts to redress the reductionism of biomedicine by focusing on meaning in illness and medical practice. It views illness as socially and culturally embedded. The ill person's experiences and responses are shaped by social explanations and practices and by "systems of symbolic meaning" (Kleinman, 1978a, p.427). The 'explanatory model' is a conceptual framework which has been introduced as a means of investigating patients' understandings of their conditions as well as comparing these with the perspective of clinicians (Kleinman, 1986; Kleinman et al, 1978). The explanatory model includes the dimensions of: aetiology, onset, impact, mechanics, course and severity of the illness; treatment issues; problems and fears associated with the illness. The model can be elicited by inquiring of the patient what has caused the problem, why it began when it did, etc. It functions partly to integrate the illness into daily life and to give coherence to the effects of the illness. It contains ambiguities and contradictions and changes dynamically over time and circumstances. It incorporates popular, professional and personal health beliefs and experiences, and will be permeated by biomedical categories of understanding, given this model's dominance.

It is not suggested that all clinicians using the biomedical model are unconcerned about 'illness'. Neither is it argued that medicine is a unitary institution comprising one homogeneous theory, set of beliefs and practices. The explanatory models of medical practitioners themselves are not consistently biomedically based; clinical application will generally differ from the theoretical and professional 'ideal' (Stein, 1986). A clinician's practice is influenced by the medical specialty and the doctor's training, clinical experience and personality (Gaines & Hahn, 1985; Helman, 1984), his/her countertransference and the particular clinical interaction (Stein, 1986).

The argument that illness understandings and experience are culturally embedded is not meant to imply that they are determined by a reified, bounded 'ethnicity' or 'culture' or that, in the South African setting, there are unitary and contrasting traditional/third world African and Western views of illness (Boonzaier, 1988). Culture therefore should not be viewed as a defining feature or possession of a group (Thornton, 1988). Cultural systems have been defined as lying "outside the boundaries of the individual as such, in that intersubjective world of common understandings into which all human individuals are born ..." (Geertz, 1966, quoted in Littlewood, 1990, p.50). Explanations of illness should not be conceptualised as a set of fixed and enduring beliefs separate from daily practices. The construction and transformation of illness explanations is an ongoing process in the context of the social environment and the themes of daily living (Hunt, Jordan & Irwin, 1989). The medical interaction is but one stage of this process; the doctor's diagnosis is generally transformed and incorporated into prior conceptions and particular life circumstances.

1.2 Clinical interactions and settings

Kleinman et al (1978, p.254) have spoken of the "cultural construction of clinical reality" which refers to doctor-patient transactions and negotiations about the illness complaint and therapeutic goals.

The 'cultural hermeneutic model' (elucidated by Good & Good, 1980) offers an alternative to the dominant biomedical approach to clinical practice. It aims to evaluate explanatory models and the meaning of symptoms in order to understand and intervene in the patient's illness reality. Discrepancies in explanatory models of doctor and patient may result in medical treatment which is clinically ineffective and unsatisfactory to patients. Such problems may be resolved by eliciting the explanatory model of the patient in the context of family and personal histories, presenting the doctor's explanatory model in an accessible manner, openly comparing these models, negotiating conflicts between them, and listing illness problems and proposed interventions (Kleinman, 1978a; Kleinman et al, 1978). This approach may improve communication and facilitate the implementation of therapeutic strategies which leave both clinician and patient satisfied (see, for example, Blumhagen, 1982, regarding professional and 'lay' understandings of hypertension and 'Hyper-Tension'). It encourages humanistic health care which is based on insight into the patient's experience and a foregrounding of illness problems and psychosocial issues. It also requires self-awareness and empathy on the part of the clinician.

Clinical practice incorporates a set of relationships, institutions and power dynamics which go beyond the dyadic interaction between doctor and patient, and extend into medical institutions and the social system (Aiken & Mechanic, 1987; Lock & Gordon, 1988). It is therefore believed that negotiation of conflicting understandings in a clinical interaction, as advocated by interpretive approaches, is not a simple matter of differences being talked out by equal partners. Attempts to resolve communication difficulties within the clinical dyad may founder unless power issues are taken into account. It therefore follows that (as argued by Kleinman, 1980) medical anthropology would have to offer a new theoretical paradigm for health problems and health care in order to challenge the powerful biomedical model and significantly alter the organisation and practice of health care. Critics of 'conventional' medical anthropology would regard it as theoretically and clinically 'hamstrung' from achieving this goal. This critique (see Singer, 1989) asserts that hermeneutically-oriented medical anthropology focuses on microlevel processes and pays insufficient attention to social relations, power dynamics and the political economy of health (macrolevel analysis). In the clinical sphere, it is argued, professionalisation of the applied work of medical anthropology has had conservative effects; concepts are translated for use by health care professionals within the biomedical paradigm.

'Critical medical anthropology' (Baer et al, 1986; Singer, 1989; Taussig, 1980) has arisen as a challenge to conventional medical anthropological approaches and investigates medical practice and doctor-patient communication within the social relations underpinning medical discourse. It thus attempts to incorporate macrosocial processes within an analysis of individual subjective illness experience. The limitations of a 'critical medical anthropology' have been shown (see, for example, Csordas, 1988; Estroff, 1988); these debates will not be discussed. However it may be noted that the danger lies, on the one hand, in neglecting historical and material conditions and prioritising personal and cultural symbols or, on the other hand, in viewing the patient as passively controlled by a biomedical 'system' and each clinical encounter as determined from above. For explication of the links between subjective experience, clinical practice and macrostructures, both cultural-interpretive and political-economic analyses are needed.

Feminist writers have been concerned with gender issues in medicine and health care and the medicalising of women's lives by a male dominated profession (Ehrenreich & English, 1973; Fisher, 1988; Gottlieb, 1987; Oakley, 1987; Olesen & Lewin, 1985). Fisher has examined the links between social structures and the microlevel of medical interactions (doctor and female patient), arguing that language reflects and sustains power structures. The doctor-patient relationship is asymmetrical with regard to decision-making and the exchange of information. A detailed feminist analysis of gender issues in medical practice has much to offer any study of illness and health care. While this is beyond the scope of the dissertation, it should nevertheless be noted that the aims and approach of this study are pertinent to feminist concerns regarding women and health.

1.3 Health care systems and help-seeking

A health care system may be broadly conceptualised as a combination of health beliefs, social institutions, personal relationships and clinical settings, all of which are relevant to a particular illness episode (Kleinman, 1980). Healing involves both the aspects of control of the disease and the search for meaning in the illness and its treatment (Kleinman, 1978b). Three domains of health care have been delineated - professional, popular and folk - which incorporate different settings, practices and explanations of sickness (Helman, 1984; Kleinman, 1980). The folk sector includes nonprofessional and indigenous (e.g., 'traditional' and church) healers. Most health care (and health maintenance) occurs in the popular sector - lay healing relationships, social networks, family and community help. Professional, popular and folk health care systems are likely to be used simultaneously and should not be regarded as discrete and autonomous entities.

From what has been said thus far it may be seen that patterns of help-seeking (one aspect of illness behaviour) are linked to a complex web of factors - including the evaluation of symptoms, explanations of the disease, life circumstances, gender, class and the availability of health care services. Consultation with medical professionals is one stage of a process of help-seeking and is rarely the only avenue used by the patient (Zola, 1980). Decision-making patterns in health seeking are more influenced by psychosocial factors than by the actual symptom (Zola, 1973). Factors which mediate the decision to seek professional help include characteristics of the social network (McKinlay, 1973), personal predispositions (Mechanic, 1986) and extent of interference with daily activities (McKinlay, 1980). The social network is generally involved in all stages of help-seeking: negotiations about the type of help which is required, lay referral and treatment, interaction with the professional and folk sectors and ongoing treatment and rehabilitation (Kleinman, 1980; McKinlay, 1980). Women tend to be the major caregivers within the private domain of the informal health care system and they are frequently mediators of family members' contact with professional health care (Graham, 1985).

'Non-compliance' with medical advice and treatment has been identified as a major problem in medical care. It may be argued that the concept of non-compliance is derived from the biomedical perspective and prioritises the doctor-patient relationship over other avenues of assistance. It also tends to ignore the social organisation of the health care system including the availability and accessibility of services. Much of the research in this area locates the problem within the patient and makes assumptions about non-compliant personality traits which can be identified and controlled. Critical views of non-compliance see it as derived from conflicting explanatory models (Kleinman, 1978a), structural factors in the relationship between doctor and patient (Zola, 1980), patients' incorporation of treatment into their daily lives and attempts to control symptoms within the demands and constraints of everyday life (Hunt, Jordan, Irwin & Browner, 1989). Trostle (1988) has argued that medical compliance has an ideological function in that it invests authority in the medical practitioner and legitimises certain values and practices. Thus what is called for is a critical analysis of the dominant models and practices of medicine and psychiatry, their social construction and their ideological aspects (see Hahn & Gaines, 1985; Kleinman, 1987, on psychiatry; Lock & Gordon, 1988; Swartz, 1989, on cultural issues in South African psychiatry).

1.4 Images of disease

Images of a disease and of the sick person are created through the social interpretations of signs and symptoms (Gilman, 1988). Disease comes to be used as a metaphor (Sontag, 1977) in that feelings are projected onto the disease and then projected outward. Particular symptoms and disorders have cultural significance in different social systems and historical periods. Kleinman (1988b) argues that the conditions in twentieth century Western societies which have most cultural salience are cancer, heart disease and sexually transmitted diseases. Gilman contends that the Western image of disease is based on a fear of collapse and of loss of control. Moral judgements about the disease and the sick person are also brought into play. Thus for example contemporary images of cancer are of a "corroding evil" (figurative definition, Chambers Twentieth Century Dictionary, 1972) against which aggressive measures and defensive strategies are required.

Dominant images of cancer (see Sontag, 1977) speak of an abnormal dangerous growth which spreads throughout the body in a slow, insidious fashion, involves invasion by lethal cells and leads in a degenerative process to the terminal stage and ultimate death. The disease process and the fight with it takes place 'inside' the body. In being associated with death and amputation, it is considered something shameful and therefore to be hidden. Views of cancer as caused by particular personality traits and repressed emotion may cast blame for the disease on the individual. Use of the term 'cancer' can arouse strong emotions; it is therefore frequently employed in political discourse.

Lipowski (cited in Pfifferling, 1980) has postulated that illness may be perceived in various ways: as challenge, enemy, punishment, weakness, relief, strategy, value or irreparable loss/damage. These attitudes are associated with particular emotional responses and coping strategies. For example, the person who views illness as a challenge will respond with active goal-oriented behaviour aimed at overcoming the problem. Illness viewed as punishment invokes a moral dimension and associated emotional response. Illness as 'enemy' conjures up images of combating forces, with potential reactions of aggressive action, passivity or avoidance. Viewing illness as weakness may lead to feelings of guilt and shame; illness as 'relief' may be associated with freedom from work and social responsibilities; 'value' implies opportunity for growth, and so on. The particular styles of patient and doctor will be played out in the communication and transference of the clinical interaction. The particular illness styles which are socially dominant and highly valued are revealed in media accounts which acclaim those who use an illness experience positively and who challenge and combat the disease. In this socially constructed framework it is thought to be possible to defeat or transcend the disease by one's strength and determination, a victory of will and of state of mind.

1.5 Illness narratives and illness meanings - Kleinman's model

Illness narratives

Kleinman's research has been primarily in the field of 'cross-cultural' psychiatry. His writing, however, has significance for illness and the practice of medicine generally. His recent book on 'illness narratives' (1988b) deals particularly with chronic disorders and asserts the importance of meaning in medicine. In the interpretive framework he presents, illness experience is conceptualised as a communicative and social experience; illness meanings are shared and exchanged. The narrative of the illness is used by the sick person to order events and experiences; it therefore both reflects the illness experience and helps shape it. "Patients order their experience of illness ... 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). Lang (1989) has demonstrated how illness narratives are used as active ways of communicating the life context of illness. Social discourses include talk about illness, thus giving meaning to events as well as soliciting support. The circumstances in which the story is told will necessarily transform the product. The clinical or research account therefore entails a construction of illness meanings in interaction with the informant. This issue is further elucidated by Gergen (1988) who has argued from a social constructionist position that self-narratives are socially produced and influenced in part by the context of the story-telling, literary forms, norms and personal goals. Seen from this perspective the narratives do not represent the person's 'true' personality traits, beliefs and behaviour but are changing expressions. The accounts of patients, doctors and researchers are therefore not simple reflections of 'reality'. This approach highlights social rather than cognitive processes.

Illness meanings

> ... Illness both brings particular meanings to a sick person's life world (e.g., the threat of death, the loss of valued body image, ...) and also crystallizes those special meanings in his/her world that constitute and express a particular form of life (e.g., cancer in the context of a desperately unhappy middle-age marriage, ...) (Kleinman, 1986, p.149).

Kleinman identifies four layers of illness meaning; these will be discussed in brief, with the understanding that they operate simultaneously and are complementary perspectives on the total illness experience.

a. Symptom as meaning

This level refers to the conventional meaning attached to a symptom, for example that a breast lump might mean cancer, that headaches signify distress or that pain means disability. Consultation about the symptoms and bodily functions occurs; this might lead to a medical diagnostic procedure, whereby symptoms and complaints are translated into signs of disease within the clinician's meaning system. In the case of cancer, a lump in the breast then becomes 'benign breast lump' or 'breast cancer'; the woman becomes a 'patient'. New meanings are brought to the experience as the illness is transformed.

b. Cultural significance as meaning

This level of illness meaning refers to that which is 'carried to' sick people. Cancer is commonly considered a highly dangerous and uncontrollable disorder which is associated with industrialised Western society and testifies to the human-created dangers of contemporary living. It symbolically challenges value systems which are based on control, orderly progress and practical scientific solutions. (See discussion above, 1.4.)

c. Life world as meaning

This refers to the significance of the illness within the person's life world (personal, interpersonal and social dimensions) and includes inner experience, relationships, work, leisure activity, self-image and personality as well as health settings and health-care interactions. The illness experience is incorporated and integrated into daily living. This level of meaning has most direct clinical relevance; for example, the person's style of expressing problems, losses involved, coping strategies and supports.

d. Explanation and emotion as meaning

This layer of meaning refers to the explanatory models, interpretations and associated emotions of the ill person and those in contact with him/her. Shared understandings facilitate the symbolic control of the experience and provide motivation for action.

Kleinman asserts the clinical relevance of this framework in that use of the narrative can ameliorate illness problems and limit disability. Thus in a clinical setting one could draw together and work with the patient's illness narrative; interpret the various types of meanings by exploring the person's life history, personality, coping styles and current circumstances; reveal the most pressing issues for that person and family and analyse the structure of the story to clarify these issues. The doctor's model should also be presented, explained and discussed. The major consequences of the illness (psychological, interpersonal, occupational, leisure) can be defined and appropriate therapeutic interventions selected (advice, problemsolving, counselling, referral etc.) and later assessed. While practical interventions may or may not be possible, it is likely that therapeutic benefit will have been derived from having supported and collaborated with the patient.

Thus far in the dissertation important theoretical concepts regarding illness experience and health care have been presented and discussed. I turn now to focus on the breast cancer literature.

2. Breast cancer

2.1 Epidemiology, risk factors and treatment

Breast cancer is the most common cancer among women (26%) in the United States (Leis, 1989a). Until recently it was also the leading cause of death from cancer among women in that country (overtaken by lung cancer in 1985). Approximately one in ten women will develop breast cancer at some point in their lifetimes. Men comprise less than 1% of those with breast cancer. Black women have a lower incidence than white women in the United States, but this is on the increase (Vernon et al, 1985). A poorer breast cancer survival rate has been associated with lower socioeconomic status, which in turn is related to late diagnosis at advanced stage disease (Freeman & Wasfie, 1989).

Breast cancer epidemiological studies have yielded 'risk factors' which are implicated in the development of the disease, including genetic, hormonal and immunological factors, exposure to carcinogens (such as radiation), and personal and demographic features (Leis, 1989a). The incidence of breast cancer rises sharply with age and higher risk is associated with previous breast cancer and a family history of breast cancer. Other risk factors include a history of benign breast disease, late age at first pregnancy and obesity (McLellan, 1988). The risk factors are numerous and are not clearly defined (Gudgeon, 1988).

Cancer public education programmes generally target high risk individuals and social groups in the hope of encouraging behavioural and lifestyle changes (Marshall & Graham, 1987). Early detection and diagnosis of breast cancer (through breast self-examination and prompt medical consultation on discovering breast symptoms) have been advocated to ensure better prognosis. Prognosis in fact relates to a number of factors such as the stage, location and growth potential of the cancer when diagnosed, as well as immunological factors and adequacy of therapy (Leis, 1989b). 'Delay' in seeking medical help does not therefore inevitably result in a worse prognosis; however a greater proportion of patients with long delays are in advanced stages of breast cancer and therefore have poorer survival rates than those with short delays (Charlson, 1985). Five-year survival rates for breast cancer have been reported as: 85% for stage 1 (no lymph node involvement or metastases), 66% for stage 2 (positive nodes, no metastases), 41% for stage 3 (significant local spread) and 10% for stage 4 (metastases) (Dent et al, 1984). Survival in this sense is a statistically derived concept and relates in part to stage of disease and efficacy of treatment. It does not of course imply cure, or indicate quality of life.

The treatment of breast cancer has advanced considerably over the decades. Initially treated predominantly by radical mastectomy, more recently conservative treatment options (limited surgery such as lumpectomy followed by radiotherapy) have become increasingly popular and found to be as effective in many cases of early breast cancer (Dent & Hacking, 1983; Ellis, 1987; Fisher, 1989).

2.2 Breast cancer in South Africa

South African cancer statistics indicate that the incidence rate and risk factors for the white population approximate those of America and Europe. Overall breast cancer is approximately five times more common among white and Asian women than among African women (National Cancer Association of South Africa [NCA], 1988). The incidence of breast cancer in the African population is rising (Walker, 1989). Mortality figures for 1984 show that breast cancer accounted for 20,4% of total cancer deaths among white women, 15,9% among 'coloured', 16,8% among Asian and 8,1% among African women (South African Medical Research Council, 1987). The 1986 National Cancer Registry (the latest figures available) revealed that the top three ranking cancers by incidence (corrected for age) were: skin, breast and colon cancer for white women; cervical, breast and oesophageal cancer for African women; cervical, breast and stomach cancer for 'coloured' women and breast, cervical and uterine cancer for Asian women (NCA, 1988). These statistics must be viewed with extreme caution due to the numerous problems and inaccuracies in collecting morbidity and mortality statistics, particularly within black communities in this country.

A retrospective analysis of cases seen at the Breast Clinic, Groote Schuur Hospital, Cape Town, during the period 1971 - 1981 (Hacking et al, 1984) showed that of the 2215 new female breast cancer patients, 49% were white, 48% were 'coloured' and 3% were African. The mean age of African patients (49 years) was younger than that of 'coloureds' (53 years) and of whites (60 years; similar to the UK and USA). A breast lump is the most common method of presentation; nipple discharge, pain and other complaints are less frequently reported (Dent et al, 1984). Patients with early breast cancer numbered 47% of the total. Most white patients presented with earlier stage breast cancer whereas the majority of black patients presented in the advanced stages. Over the period under study the overall proportion of patients presenting with early breast cancer increased, except in the case of African patients. Noting the extent of late stage presentation, the authors emphasised the need for breast cancer education programmes particularly in black communities.

2.3 Psychosocial aspects of breast cancer

The literature on psychosocial aspects of cancer (and breast cancer specifically) falls into several broad areas:

- the role of psychological and emotional factors in the onset and progression of cancer
- the determinants of health-related behaviour and factors associated with 'delay' in medical consultation following onset of cancer symptoms
- the psychosocial impact of cancer and factors associated with adjustment
- psychological responses to cancer treatment
- psychosocial interventions for cancer patients.

A selected review of the literature will be presented within the above categories.

Psychogenic hypotheses

It has been postulated that a particular personality type characterised by lack of emotional expressiveness, suppression of negative emotions and sense of helplessness may predispose to cancer (Gross, 1989). Life stressors such as the loss of a significant attachment figure, and emotionally distant parents may also be implicated (Stolbach & Brandt, 1988). Poor outcome in breast cancer has been associated with particular coping styles, such as listlessness, stoical acceptance and suppression of hostility (Hu & Silberfarb, 1988; Magarey, 1988) and conformity and passivity (Goldstein & Antoni, 1989).

Research in this area is fraught with methodological problems (Gross, 1989; Hu & Silberfarb, 1988; Redd & Jacobsen, 1988). These include difficulties in dating the onset of the disease, complexity of biochemical processes, inaccuracy of patients' recall of events, use of measurement tools with limited validity, lack of clarity in terminology and concepts used, lack of regard for the effects of different types of cancer and lack of control groups. Comparison between studies is problematic as different methods and measures are employed. Research findings on causal links between psychological factors and cancer have been contradictory and inconclusive (see Cooper, 1988; reviews by Greer & Morris, 1978 and by Redd & Jacobsen, 1988). The nature of the interaction between psychological processes, biological mechanisms and biochemical changes remains baffling.

Health behaviour and 'delay'

Breast cancer public education programmes emphasise the importance of breast self-examination (BSE) and prompt medical consultation following onset of breast symptoms. The efficacy of these programmes and the determinants of 'health behaviours' have been investigated (Calnan & Rutter, 1988; Rimef, 1976;

Siero et al, 1984; Waters & Nichols, 1982). Theoretical models such as the Health Belief Model (HBM) have been developed to explain the relationship between beliefs and health-related behaviour such as BSE performance (Calnan, 1984; Champion, 1985; Lauver & Angerame, 1988; Ronis & Harel, 1989).

A large body of psychological research has focused on the reasons for delay in presentation for medical treatment, with a view to identifying more effective methods of influencing women to seek help promptly (see Greer, 1985, for a review of research on cancer patients generally). Studies have produced varied, and sometimes contradictory reasons for delay. These have included concern over the tumour and denial of anxiety (Cameron & Hinton, 1968) linked to fear of a diagnosis of cancer and of disfigurement from mastectomy (Greer, 1974); ignorance about cancer symptoms (Hughes, 1987); presenting symptoms other than a lump (MacArthur & Smith, 1981; Nichols et al, 1981); poverty, lack of resources and a fatalistic attitude to life (Shukla et al, 1981). Gregorio et al (1983) found a tendency for black women to delay longer than white women while Vernon et al (1985) claim that 'ethnic difference' is not an important factor in delay. Psychoanalytic concepts have been used to explain delay, particularly with regard to the defence mechanisms employed to deal with the emotional impact of discovery of symptoms, for example denial, suppression or rationalisation of the meaning of the symptoms (Gyllensköld, 1982; Todd & Magarey, 1978).

A study in three hospitals in the Cape found that during the period 1974 - 1987, a far greater proportion of African patients presented with advanced stage breast cancer (75%) as compared with 'coloured' (49%) and white (21%) women (Hacking et al, 1988). Given this problem, Hacking et al recommended improved doctor-patient communication, involvement of the patient's social network in treatment, cancer education programmes in conjunction with traditional healers (who are frequently consulted prior to doctors) and management strategies which are appropriate to African cultural beliefs.

Many of the delay studies have concluded that delay in presentation results from non-rational unconscious factors, most commonly identified as denial (Greer, 1985), which may not be influenced by public health education appeals. Nevertheless programmes impart information and increase breast cancer awareness in the hope that the well-informed person will comply with their recommendations (behavioural change, use of medical services). Given the complex relationship between knowledge, beliefs and subsequent behaviour, this assumption is a controversial one. Research on health-related behaviour which uses a cognitive-behavioural framework (such as the Health Belief Model) is limited in explanatory ability by its assumptions of human rationality and autonomy in information-processing, decision-making and translation into behavioural change (Good, 1986). A challenging view of the issue of 'risk' and behavioural change has been presented by Gifford (1986) who distinguished between epidemiological (and statistical) use of the concept of risk, its clinical application by doctors and the 'lay' person's lived experience of risk. It was asserted that factual information about the risks associated with the development of a disease will not necessarily lead to behavioural change (e.g., BSE) unless risk is transformed into a subjective experience which is felt to have personal significance.

It is argued that the notion of delay is a biomedically based conceptualisation of the period between onset of symptoms and the encounter with a health professional. It neglects the significance of the patient's other help-seeking behaviours and often does not address the issue of accessibility of health services. It contains implicit assumptions of passivity, poor judgement and 'bad' behaviour on the part of the patient. Twaddle (1980) argues that the medical system places patients in a double bind by imposing contradictory expectations for behaviour: the patient must not waste the doctor's time with minor complaints but must also not delay in seeking medical help.

Psychosocial impact and adjustment

Psychological morbidity among cancer patients has been associated with fear of death and of mutilation, anxiety about possible recurrence, loss of autonomy and a sense of alienation and isolation. The impact of the disease is inseparable from the effects of the cancer treatment. (See Ahmed, 1981; Cohen et al, 1982; Cooper, 1988; Cullen et al, 1976; Greer, 1985; Vaeth, 1986.) Methodological problems with cancer research in this area have been noted, for example neglect of the influences of age, gender and religion (Freidenbergs et al, 1982) and lack of validity and standardisation of certain psychological scales used for measurement (Redd & Jacobsen, 1988).

Resolution of most life crises occurs through the resources of the individual and his/her social networks rather than the utilisation of professional interventions. Factors which have been associated with adjustment to breast cancer include: emotional status, sense of self-worth and feelings about sexuality (Golden, 1983); culturally based coping responses (Baider & Sarell, 1983); personal style of coping with stress (Blumberg et al, 1981); spousal support (Baider & De-Nour, 1988; Peters-Golden, 1982) and good social support generally (emotional and material) (Bloom, 1982; Zemore & Shepel, 1989). Satisfaction with the assistance of medical professionals (particularly with regard to information-giving) is also a significant factor (Neuling & Winefield, 1988).

The fear and stigma surrounding cancer may result in avoidance of the cancer patient and thereby removal of social support. Peters-Golden (1982) compared perceptions of social support among breast cancer patients and a group of 'healthy' men and women. The majority of patients reported having been avoided, feared and pitied since becoming ill. They felt restricted by expectations of socially acceptable sick behaviour and other people's false optimism. Women who had undergone mastectomies complained that while their main concern was of the suffering of cancer and threat of recurrence, those around them focused on the breast loss and associated injury to feminine self-image. It was argued that cancer patients' experience differs significantly from the perceptions of the healthy. Support is frequently not available and when it is might be inappropriate and conditional. This may lead to feelings of isolation and alienation and to adjustment problems.

A model of cognitive adjustment to threatening situations has been elucidated by Taylor (1983) and used to examine the coping strategies of breast cancer patients. This schema identifies core concerns as being the search for meaning, attempts to regain control and the restoration of self-esteem. It was shown that self-enhancement ensued from 'downward' social comparisons (with less fortunate real or hypothesised people). Facts and events were reframed in a positive way in order to maintain a sense of mastery. Better adjustment was not significantly associated with particular attributions of causation but rather with perceived control of the breast cancer (Taylor et al, 1984).

Ray et al (1982) have proposed that underlying a person's coping strategies are various coping themes - rejection, control, resignation, dependency, avoidance and minimisation - each of which is associated with particular defence mechanisms. The coping strategies of breast cancer patients have been investigated using this schema. For example 'control' refers to active attempts to master the challenge and may be accompanied by intellectualisation. In contrast, 'dependency' refers to reliance on external resources and a subjective experience of powerlessness, which may be associated with regression. The ill person generally employs more than one coping theme at different stages of the illness and in diverse contexts.

It is argued that coping occurs within a context of interpersonal relationships, support networks and health care systems. Thus the coping responses of a woman with breast cancer may be defined as context-specific strategies rather than a reflection of a lifelong coping style which she employs in each stressful situation she encounters. Bard and Sutherland (1955) have contended that reactions to different life crises vary and that a woman's response to the particular stress of breast cancer will not merely reflect a standard reaction to all traumatic life events. In addition reactions and coping responses will change over the course of the illness.

Psychological responses to treatment

Psychiatric morbidity has been associated with chemotherapy (Greer, 1985; Morris, 1983). Patients undergoing radiotherapy may experience significant emotional upheaval and distressing physical symptoms (Forester et al, 1985). This discussion focuses on mastectomy which has received extensive research and clinical attention.

Studies on the psychosocial effects of breast cancer have emphasised the psychological significance of the breast in relation to femininity and sexuality, for example by demonstrating that breast cancer has disruptive effects on body image and sexual functioning (Golden, 1983; Gyllensköld, 1982; Vaeth, 1986). The experience is mediated by socially determined ideas about desirable body shape, size, structure and functioning (Helman, 1984; Osborne, 1984). Studies have suggested that women treated with breast conserving surgery face less of a loss and a more limited disturbance of sexual identity and body integrity than those who undergo mastectomies. As a result they have a more positive body image and fewer sexual problems (Bartelink et al, 1985; Beckmann, Johansen, Richardt & Blichert-Toft, 1983; Lehmann et al, 1989). Gyllensköld (1982) used a psychodynamic framework to investigate women's experience of the disease over a period of two years. Defence mechanisms were employed against the anxiety induced by the threat to life and to feminine identity. It was suggested that certain defences, such as suppression and reaction-formation, may be reinforced by medical staff's attitude.

Maguire et al (1978) found that one year after mastectomy a significant number of women (39%) showed psychiatric problems (anxiety and depression) or sexual problems, as compared to those who had undergone surgery for benign breast conditions (12%). It has been postulated that psychiatric morbidity may be evident only some time after mastectomy as denial operates initially to protect women from sexual conflicts and loss of self-esteem (Jamison et al, 1978; Polivy, 1977).

Several reviews of the literature on the effects of mastectomy on psychological and sexual functioning have been published. Morris (1983) reported that between one-quarter and one-third of women will suffer emotional distress or sexual problems after mastectomy. Beckmann, Blichert-Toft & Johansen (1983) concluded that mastectomy frequently results in depressive and anxiety reactions related to a fear of cancer and of disfiguring surgery. It was claimed that these are 'normal' responses, which may however be regarded as psychopathological if they are persistent and severe. Gerard (1983) found that one-third of women who have undergone mastectomies will experience a deterioration in sexual functioning, particularly prominent in the first three to six months post-surgery. She argued that long-term effects have not been adequately researched.

Zemore & Shepel (1989) have challenged the widespread belief that mastectomy results in maladjustment and reduced social support. They found that early stage breast cancer patients who had mastectomies did not show poorer social and emotional adjustment than the control group of patients with benign breast lumps. In addition the mastectomy group reported greater social support and closer family ties than the control group. Marital and sexual difficulties post-mastectomy may be influenced by the nature of the relationship prior to the illness, the couple's communication and the spouse's response to cancer (Baider & De-Nour, 1988; Bard & Sutherland, 1955).

A questionnaire-based survey of post-mastectomy adjustment among 100 white women in South Africa (Nel et al, 1985) found that 87% of women had resumed usual activities, generally within three months. A significant proportion experienced short-lived emotional problems (42%) and physical problems (39%). These difficulties were more evident among women who were young, single and in a low income group.

The majority of women (80%) expressed satisfaction with their physical appearance. One-third of patients reported having been inadequately briefed about treatment options and the possible effects of mastectomy. In another South African study, O'Hare & Wissing (1988) used psychological scales and a questionnaire to investigate the effects of mastectomy on a group of white married women. They found that mastectomy did not have deleterious effects on self-concept and sexual relationships except among peri-menopausal women. They attributed good adjustment partly to the use of defence mechanisms. Both these studies recommended counselling and rehabilitation programmes to facilitate adjustment to mastectomy.

Peters-Golden (1982) cautioned against assuming the centrality of the issue of breast loss post-mastectomy; other fears may be more prominent. Similarly Bard & Sutherland (1955) rejected claims about the general meaning of breast loss for all women and argued that reactions to mastectomy vary according to the particular significance of the breast for each woman.

Psychological interventions for women with breast cancer are apparently based on an evaluation of their experiences and their needs, derived from research findings. Rosser (1981) has criticised the conceptual and methodological basis of much of the psychological literature on mastectomy for having a limited analysis, being based on a reductionist medical model and being unable to make sense of the complexities of the illness experience of women with breast cancer. She argues that: (a) studies separate the experience of having breast cancer from the experience of the treatment of mastectomy; (b) women's responses to mastectomy should rather be seen in relation to their fears of cancer and of death, and their ideas about the efficacy of medical treatment; (c) arguments for the significance of the breast loss tend to prioritise the issue of physical attractiveness to others and to neglect the general experience of loss of a body part; (d) there are implicit definitions in the literature of 'normal' coping responses, based on assumptions about women and their social roles (as mother, wife), with associated moral judgements; (e) assumptions are made of unchanging reactions linked to particular personality types whereas each woman will develop her own way of coping and emotional responses will change over time. Rosser concluded that there have been few attempts to explore women's subjective accounts in order to reach an understanding of the meaning the experience holds for them.

Psychosocial Interventions

A variety of psychosocial interventions have been used with cancer patients with the aim of treating psychological disturbance or improving level of functioning and quality of life. Treatment options have included rehabilitation groups, supportive psychotherapy, cognitive-behavioural therapy, group therapy, family counselling and self-help groups. The psychosocial dimension is generally regarded as the domain of the counsellor, frequently a psychologist or social worker. Mental health professionals may be called on as consultants for management issues or to treat patients who require psychiatric help.

Individual psychotherapy during radiotherapy treatment has been found to reduce emotional and physical symptoms substantially. This might be due in part to the general benefits derived from ventilation of feelings within a supportive environment (Forester et al, 1985). Behaviour therapy has been used for pain control and alleviation of the side-effects of cancer treatment, with some positive results (Redd & Jacobsen, 1988).

Counselling of the mastectomy patient may proceed in stages depending on the issues pertinent to each period of the illness. Early crisis intervention for breast cancer patients has been recommended in order to facilitate the development of positive coping strategies (Lewis & Bloom, 1978). Pre-mastectomy counselling has been advocated (Battersby, 1981; Jamison et al, 1978) and counselling following mastectomy has been found to be of benefit (Greer, 1985; Maguire et al, 1983). A crisis counselling programme was initiated and later evaluated at a hospital in Cape Town (Hales, 1986) and found to aid women's psychosocial adjustment (as assessed by self-report questionnaires). The work of lay counsellors in mastectomy advisory services and cancer associations has been commended (e.g., O'Sullivan, 1982; Wiesenthal, 1984).

Support, validation of feelings, information-giving and referral are among the tasks of the counsellor (Golden, 1983). Interventions could usefully focus on the relationship between self-esteem, body image, life stage and sexuality (Schain, 1986). Magarey (1988) advocates expressed hostility as a goal in counselling and proposes that medical practitioners are trained in counselling skills so as to facilitate patients' verbalisation of their distress. In contrast Watson et al (1984) argue that healthy coping need not involve active confrontation of the problem; denial of the seriousness of the diagnosis may be associated with short-term psychological benefits.

Redd & Jacobsen (1988) suggest that psychological treatment of cancer patients can be of benefit but methodological problems prevent conclusive findings in this regard. In addition the relative effectiveness of particular psychological interventions is unclear (Freidenbergs et al, 1982; Watson, 1983). Watson has advocated the application of clearly directed interventions with those who show a vulnerability to stress, rather than the provision of general programmes to everyone.

The stress on health professionals working with cancer patients has been reported (Freidenbergs et al, 1982). Taylor (1988) has investigated the strategies employed by doctors to communicate the diagnosis of breast cancer to patients, influenced by their anxieties, philosophy of medical care and the hospital ethos. The medical practitioner's power to influence the cancer patient's experience positively (in providing support, empathy, information) has been emphasised; negative determinants include the fragmentation and specialisation of medical care and its curative focus (Bloom, 1981). Morris (1983) has suggested that barriers to effective psychological treatment lie in public and professional fear of cancer and sense of powerlessness in the face of the disease. In his work on chronic illness, Kleinman (1988b) has argued that contemporary biomedicine focuses on cure and control of disease processes and fails to confront the patient's life problems and ongoing needs: that which is central to the healing of chronic illness, is neglected.

Perspectives in the literature

Many of the studies on psychosocial aspects of breast cancer cited in this introduction have yielded extremely interesting and useful findings which have aided the care of breast cancer patients. However perusal of the literature highlights the following limitations. Firstly, much of the research tends to divorce the impact of breast cancer from the rest of the woman's life. This results in fragmentation of the woman's experience and neglect of the dimensions of daily living. Secondly, empirical studies have frequently employed psychometric methods of measurement (questionnaires, inventories) resulting in psychosocial concomitants being categorised and presented in a static way. Similarly personality, emotions and beliefs are frequently depicted as stable consistent qualities rather than as changing social constructions and expressions. Potentially contradictory responses and dynamic changes in response over time remain hidden. Thirdly, measurement of responses to the illness which are based on implicit definitions of health, self-worth, femininity, etc. may have associated judgements about appropriate behaviour and responses. These notions may be derived from a biomedical perspective. Fourth, there is an emphasis on the experiences of heterosexual and married women. Fifth, little attention is paid to the influence of the health care system and clinical interactions on the illness experience. The limitations of conceptual models of the breast cancer experience are likely to result in obstacles to effective psychosocial interventions. (The psychodynamic work of Gyllensköld, 1982, and the approach of Bard and Sutherland, 1955, and of Rosser, 1981, have in different ways addressed these limitations and considered the issue of meaning.)

It appears that the insights derived from interpretive medical anthropological approaches to illness and health care have infrequently been applied to the experience of women with breast cancer. Few studies have used women's own accounts to highlight the meaning which it holds for them.

3. Aims of the study

Thus far in the dissertation I have outlined key concepts of hermeneutically-oriented medical anthropology, described Kleinman's framework for the analysis of 'illness narratives', provided a brief introduction to breast cancer and selectively reviewed the literature on psychosocial aspects of the disease. The introduction has provided a background and theoretical framework for what follows. This study approaches breast cancer from a perspective little seen in the literature on the illness. Its broad aim is to examine the experiences of women with breast cancer using concepts derived from medical anthropology and specifically applying the framework of Kleinman (1988b).

The verbal accounts of five women who were asked to reflect on their illness will be reported and discussed. Breast cancer is not one experience but incorporates numerous dimensions; it can be analysed on different levels simultaneously. It is hoped to elucidate the meanings of each woman's subjective experience of the illness in the context of her personal life history, current life circumstances and the cultural significance of breast cancer. Discussion will centre on the period from onset and appraisal of symptoms to diagnosis and treatment and a short while beyond. The usefulness of this analytical model in making sense of the women's experiences, will be considered.

It is hoped that this study will contribute to local research on breast cancer by offering pertinent insights into the experience of women with the disease. It has relevance for clinicians of various disciplines working with breast cancer (and other) patients in that it incorporates a framework for understanding illness and an associated approach to patient care.

METHODOLOGY

1. Participants

Participants in the study were chosen through the Groote Schuur Hospital Breast Clinic, Cape Town. Outpatient Breast Clinic attendance figures for the year period April 1987 to March 1988 indicate that of the new female patients approximately 16% were white, 80% were 'coloured' and 4% were African. Of the 2103 new patients during that period, 370 (17,6%) were diagnosed with breast cancer (Cape Provincial Administration, n.d.). New patients are generally referred to the Clinic by other hospitals, Day Hospitals and general practitioners; they are seen at the Friday outpatient clinic for initial medical examination and tests, are provisionally diagnosed and further tested the following week. On the Wednesday they attend a combined clinic in the Radiotherapy Department in order to finalise diagnosis and treatment plan.

The five participants were required to fulfill the following criteria: (a) new female patient with a recent diagnosis of breast cancer, (b) no previous history of breast cancer, (c) able to speak or understand English, (d) willing to participate in the study and to be interviewed immediately and at home within a few days and (e) amenable to the tape-recording of interviews. The particular five women chosen for inclusion in the study were those available during the period of data collection (Wednesdays from mid-April to mid-July 1989) who fulfilled these criteria.

Participants were all 'coloured' women. They lived in working class and middle class suburbs of Cape Town. They ranged in age from 31 to 73 years old; three were married and two were widowed. Two of the women were employed by supermarkets, one was a pensioner and two were 'homemakers' who were no longer gainfully employed. Their levels of education ranged from Standard 2 to Standard 7. Four of the women were Christian and one Muslim.

2. Interviews

An interview schedule (Appendix) was developed on the basis of a review of relevant literature and comprised the major areas to be covered; it served as a flexible guideline for the interview. A small pilot study, of three interviews with breast cancer patients, was conducted in the hospital. Briefly, the pilot study helped structure the interview schedule, highlighting, for example, the importance of focusing on social aspects of the illness; indicated the viability of the chosen venue and timing of the interviews and also confirmed that it would be important to go beyond the hospital setting for further interviews in the women's homes. For reasons of limited space, the data from the three pilot interviews will not be presented in this dissertation.

The procedure for the main study was as follows. Participants were first approached and interviewed in the Groote Schuur Hospital Radiotherapy department (in a consultation room) at lunchtime on a Wednesday. This occurred after confirmation of the diagnosis but prior to finalisation of treatment plan. Venue and timing of the interviews were determined by practical considerations. The study was introduced to the woman and confidentiality assured. At the conclusion of the first interview, arrangements were made for the second interview which was conducted at the woman's home within four days. This first set of interviews was carried out during the period mid-April to mid-July 1989.

After a period of eight to ten months had passed, the third and final interview was arranged telephonically. This time gap ensured that the treatment (which could last several months) was complete and allowed for participants' return to usual activities and routines. It was discovered at this point that one of the participants had embarked on a year-long overseas trip and was therefore unavailable for a third interview. In her case, findings and discussion will be based on the two interviews conducted. An outline of interview topics was prepared (Appendix) and the follow-up interviews were conducted in the participants' homes from March - April 1990. The combined interview time for each woman was approximately three hours.

The interviews were semi-structured. Interviews with four of the women were conducted in English which was their home language; the fifth participant was interviewed in both English and Afrikaans. All interviews were tape-recorded. This ensured accurate recall of interview material, while facilitating rapport and communication in the interview situation by avoiding note-taking. Each interview was transcribed verbatim.

3. Method of analysis

A case study method allowed for in-depth exploration of certain issues. Clearly information from such a sample cannot be generalised in the manner of large representative samples; rather the analysis is guided by a theoretical framework (Yin, 1984) with the aim, in this study, of exploring the particular experience of each woman who was interviewed. A qualitative analysis of interview material was performed using Kleinman's framework. Qualitative data analysis is well-suited to the study of the significance of events and experiences (and the study of illness meanings) and is emphasised in a hermeneutic approach to social science research. Research material may be interpreted using the analytical concepts, findings and frameworks developed in medical anthropology (Kleinman, 1986).

The research interview is more than simply a series of questions and answers; rather it is a dialogue between two people. The interviewer is both questioner and listener. Responses reflect the respondent's evaluation of the demands of the situation. The interview context is thus essentially linked to meaning (Mishler, 1986). Both researcher and 'researched' participate actively and influence each other; the research relationship is a crucial aspect of the endeavour (Berg & Smith, 1985). In addition the researcher's assumptions shape the structuring of data and the interpretation of findings (Antaki, 1988).

It is believed, as outlined by Gergen (1988), that personality and behaviour are not stable consistent entities. The respondent's particular account is distinctive and reveals the changing dynamic nature of emotions, understandings, responses and actions. What is described will shift, vary and at times be contradictory. The account will be shaped (consciously and unconsciously) by the demands of the interview and perceptions of what is most appropriate at that time. My own influence on the telling and interpretation of the stories is therefore acknowledged. My position as a white researcher and professional, first encountered in the hospital setting, will have influenced the women's evaluation of the interview situation and contributed to the power dynamics of the interaction. This might have been reflected in a need to present themselves and their illness in a way which would satisfy or please me. Attempts were made to understand this as part of their accounts, as well as to limit it, by indicating my lack of involvement with medical staff and procedure and by conducting interviews in their familiar home environments. I attempted to maintain an awareness of my potential responses (shock, encouragement, reassurance) to women 'traumatised' by a recent diagnosis of a life-threatening disease. Clinical interviewing skills were used and respect shown for the women's need to present themselves at each point in the manner that they did. It is believed that the interviews were conducted with sensitivity and empathy and were positively received, while not detracting from the validity of the interview material collected.

My aim has been to focus on the women's perspective by presenting their understandings in their own terms, in the ways they made sense of the experience. The interviews allowed for a description of the experience of breast cancer and the personal context in which it was located. The follow-up third interviews elicited information on the changing nature of the experience and offered a sense of the ongoing illness experience. Retrospective accounts do not produce accurate recall of events but, given the approach of the study, this does not affect the significance of the data.

In the following section of the dissertation I shall present the stories of the five women. Their names and places of residence have been changed for reasons of confidentiality. Age and marital status have been retained. A short note on the interview interaction will be followed by a discussion of the various levels of illness meaning, in three sections (symptoms, explanatory models and life world). Given the amount of data collected, selection and highlighting of certain parts have been inevitable. For reasons of limited space and avoidance of duplication, the 'findings' will be presented directly within the framework of the analytical model (along with discussion) rather than first presented and then analysed. Quotations (as recorded verbatim) will be used to illustrate the points which are made. The three interviews will be mentioned separately as necessary. Following the five accounts, I shall discuss the cultural significance of breast cancer, drawing on material from all the interviews.

FINDINGS AND DISCUSSION

ILLNESS NARRATIVE - Cheryl F.

Cheryl F. is a 31 year old married woman with a four year old son, living in Mitchell's Plain. Her husband of five years is a security guard and they own the four-roomed house in which they live. Cheryl has been employed as a clerical worker in a large supermarket for the past 14 years.

When I first met Cheryl in a consultation room in the Radiotherapy Department, her body was tense and she had a slight facial tic. She spoke rapidly and in detail about the events of the past few months. She was more reticent when discussing her emotional responses and the negative aspects of the illness thus far. A few days later in her home she was a great deal more relaxed in her interaction and forthcoming in sharing her experiences with me. In the third interview some months later I found Cheryl confident and self-assured. She was lively and spontaneous in her interaction and engaged me in general conversation.

She appeared distanced from what she perceived as a past traumatic experience and presented herself as having a restored sense of confidence and control.

From breast lump to 'breast cancer patient'

In the first interview Cheryl related the events of the previous four months since the day she examined her breasts (as she did regularly) and discovered a lump in her left breast. She did not initially experience any problems or disruption of her daily activities and monitored the lump over the following months: "The lump don't get bigger and it don't get smaller and it don't move; it stay right here ... it doesn't hurt me or nothing". Those she told about the lump advised her to see a doctor and have it removed: "People say if you've got a lump they just cut it out". She claims she postponed visiting the doctor as she did not consider that it could be cancer as "most people get lumps and it's not cancer and it's finished." In addition, she evaluated her personal risk of contracting cancer as minimal, given her youth and active lifestyle: "To my knowledge I'm not supposed to have that things because I'm fit, active". She consulted her private practitioner only when her son fell ill and required medical attention.

The lump was removed, tests conducted and the medical diagnosis made. Cheryl described the disease as "a touch of cancer, beginning of cancer", however the impact of the diagnosis is revealed in her statement that the expression on the doctor's face was "almost like he was giving me the (pause) death sentence". She spoke graphically, in retrospect during the third interview, of her shock, fear and distress following the diagnosis. "I never in my life cried like that, because I don't know what's going to happen; I'm going to die or what. It's horrible that moment when the doctor tells you". When she questioned her doctor about how long she had to live he reassured her "don't talk nonsense 'cos nowadays they cure breast cancer". An operation (wide local excision of the tumour) was performed a few days later. Cheryl was then referred to Groote Schuur Hospital for radiotherapy and ongoing management.

At this point it was discovered that she was four weeks pregnant and an abortion was planned. She spoke of the prospect of the abortion, hinting at her feelings of shame, guilt and sadness at the loss of her baby.

> "It feels terrible but I have to do it. I've got no other choice .... My baby, they're going to remove it now because it's not a whole baby yet and now I think, isn't it murder? ... but it's over now, it's okay. My life goes on. They must just do the thing and get done with it ... I don't look one minute back. I just look straight ahead."

Both Cheryl and her family were relieved that she had early stage breast cancer and did not require a mastectomy. She was aware that this might be a temporary reprieve and that the prognosis is always uncertain. In the second interview she spoke of her fear of recurrence of the disease. She had been told that the cancer had been excised and that she was healed but she remained concerned.

> "I don't want them to say 50%, they must be 100% sure that I'm completely healed ... That is what I want to hear. Not 50%, it's not good enough for me. Because 50% means it can come back again and after that I have to lose my breast."

The third interview took place after completion of the treatment some months later. Cheryl described the radiotherapy as having been less distressing and uncomfortable than anticipated. She was told by the doctors that she was in good health and generally regards herself as healthy as "they removed the part that is cancerous". Nevertheless she continues to fear a possible recurrence of the disease: "You had cancer, now you think you've still got it, you will die of it". She remains with a loss of confidence in her body: "You worry, you go for a checkup and you just pray, please let everything be good, okay".

Explanations and images of disease

Cheryl believed that the cause of cancer is unknown even to medical professionals. She wondered if she had unknowingly injured her breast while playing netball. She regards a lump as the first sign of cancer, however is aware that not all lumps are cancerous. Cancer is limited and controlled to begin, but "the minute your glands is touched then it spreads through your whole body". She stated that there are different stages in the development of cancer; the more advanced stages require major treatment (mastectomy in the case of breast cancer) and the late stages cannot be treated but result in death. She thought it important to discover cancer early and comply with medical treatment. "If you don't take notice it could kill you. But I was lucky I took notice of it". It appears that she felt reassured by her diagnosis of early stage breast cancer and as a result did not consider her four month period of 'delay' as significant. She stated that prior to her own experience with cancer she believed that it led inevitably and quickly to death but now agrees with friends who have assured her that many people survive for years. However it is evident from her repeated comments that she fears that the cancer still exists as a hidden danger, although no external signs are visible. In describing another cancer patient she warned: "You look nice again like a healthy person, but inside it's eating you". An appearance of well-being does not imply freedom from disease; health may be an illusion.

Living with illness - control and coping

In order to understand Cheryl's experience, we must examine that which is brought from her life to the illness. Cheryl is part of a close-knit family on whom she relies for friendship and support. Her father, a wage clerk, was pensioned five years ago after an operation. He is the central figure in the family. Her mother suffers from anxiety and depression and has received psychiatric treatment. Cheryl is one of six siblings, all of whom live in Cape Town. She left school in Standard 7, having always disliked academic work. She excelled at sport and has continued to be an active sportsperson. She was employed in a factory for a short period and then joined her present firm; she has received promotion within the clerical staff and considers her work goals to have been attained.

Cheryl met her husband, an electrician by trade, at the age of 22 and after a five year courtship married him. She fell pregnant soon after, at which point her husband was unemployed. They moved to their present home once he found steady employment. She described her husband as an understanding and hardworking but rather unassertive man. She regards their marriage as a good one. She has not had a serious illness in the past and has seldom had cause to visit a doctor.

Cheryl described herself as a happy-go-lucky person. She enjoys an independent life and during this illness has needed to impress as active, strong and in control. She maintains a positive matter-of-fact attitude: "I think you must keep yourself up". She believes she was fortunate: "It wasn't that far ... so my chance is much better than the other people" and "See[ing] people worse than you then you feel okay again". She draws strength from comparisons with those who are less fortunate and have suffered more than her.

Cheryl has concealed the disease from all but trusted friends because "they feel sorry for you, look like you gonna die any minute and I don't want that". She fears the stigma of her illness: "I want to be treated like a normal person because to me there's nothing wrong with me". She appreciates her family's support which does not include a response of pity: "You mustn't be pitied because that's the time you go down; you feel sorry for yourself". She has been deeply affected by her father's struggle with ill-health. "I learned a lot from him, never to pity yourself or to keep on saying 'ooh eina' or nothing. Go out and face the world and don't think about it. Just take yourself as a normal person. And it helped a lot."

Cheryl is intolerant of weakness and will not allow her illness to become a handicap which disrupts her life. During the third interview she reiterated: "It's all past"; "It's just part of life" and "I must just carry on my life as normal". She prefers not to dwell on the sickness as this implies acknowledgement of a problem and identification with a 'sick group'. She is therefore not in favour of involvement in breast cancer support groups. "They said people who have cancer or that kind of sick must try get together and talk. I don't see why. No, you must mix with all kind of people. You mustn't just mix with the sick people, then you feel sick." Cheryl claimed that she felt comfortable speaking in the interview situation. Nevertheless the above concerns are likely to have shaped the way she presented herself to me; they might have led to intellectualisation of the experience and a desire to present it in a positive light. She also indicated that she wished to fulfil perceived expectations of the interview by offering the details of her experience, and indicated too that she felt she had something of value to share with me.

Thus the strategies employed by Cheryl to cope with her illness are based on the underlying meanings it holds for her. Her account reveals multiple fears - of death and disfigurement, of stigma and being alien, of loss of order and autonomy - and her attempts to control and incorporate the experience into the course of her life.

ILLNESS NARRATIVE - Paula M.

Paula M. is a 45 year old married woman living with her husband and four of their six children in a two-bedroomed council flat in Elsie's River. She is employed in the bakery section of a supermarket.

I first met Paula shortly after she was told she had breast cancer. She offered few spontaneous comments and was reluctant to speak about the experience of the past few days, becoming tearful when mentioning the diagnosis of cancer. She became increasingly distracted as the interview progressed. When interviewed in her home a few days later she appeared eager to engage in the discussion and to offer her views. She related in an expressive manner, speaking in a loud definite voice. She tended to focus on her religious faith when asked specifically about the breast cancer. During the third interview she was again friendly and spoke in a self-confident manner. She complained of intermittent pain from a recent injury to her breast.

Interpreting symptoms, seeking help

Six months prior to our first interview Paula noticed blood on her dress. "It was so a shock for me. I saw the blood here out of my breast ... red blood, out of the nipple where the milk comes." On telling her family and co-workers she was advised to see a doctor because "it can turn into cancer". Paula sought medical help five months later.

> "I really don't know what keep me waiting so long. It's [that] I didn't have any pain that's why I didn't want to go that time. And I must be in my work because we were short of girls and so I didn't have time to go to the doctor ... My breast wasn't hard and I didn't have any pains. It was normal like the other one."

When told by the doctor she consulted that in fact it was a harmless discharge she felt somewhat reassured: "I thought I'm not going to worry anymore". However when she began experiencing pain two weeks later she became increasingly concerned: "The moment the pains begin, so I begin to feel it's getting hard here ... heavy pains, like a needle that sticks in my breast". She found the experience of pain particularly worrying and deserving of medical attention. She immediately consulted a second doctor who referred her to Groote Schuur. Paula's interpretation of her symptoms was mediated by her different bodily complaints, personal anxieties, social setting, medical contacts and the views and advice of those around her.

During the first interview Paula spoke about the diagnosis, "the x-ray show that it is cancer, it's a big growth", and her immediate anticipation of the loss of her breast. Her mother responded to the diagnosis by instructing her to keep it a secret, but Paula decided against this as she wished to enlist the support and prayers of members of her church (the Christian Community Church). "As ek nou vir niemand moet sê nie, en ek sê nie vir my kerkmense nie, dan hoe gaan hulle weet, hoe gaan hulle bid? Hulle moet vir my bid sodat ek kan gesond word." She reported that she would be treated with a six-month course of chemotherapy in order to reduce the size of the lump, followed by a mastectomy. She added that the chemotherapy, and more importantly the "prayers going out", would eliminate the need for a mastectomy. It transpired in the third interview that Paula was treated with chemotherapy followed by five weeks of radiotherapy. She interpreted this in a positive light; it may also be understood as an indication of the severity of her illness.

During the third interview she spoke briefly of the unpleasant side effects of the chemotherapy and of the disruption, fatigue and financial cost of daily visits to the hospital for radiotherapy. She reported that she had recently injured her breast with the sharp point of a clothes hanger." The prayers of her priest had eased the pain and she had not consulted a doctor but would wait for her next appointment. Her religious faith and the fact that the pain was not persistent reinforced her avoidance of the hospital and any further treatment. During the interview she experienced intermittent sharp pain and became increasingly concerned about a possible exacerbation of her condition. She decided to contact the hospital the following week.

Explanation through religious symbols

Paula's explanatory model lies predominantly within a religious framework, shaped by her faith and largely church-based social network. Her emotions are also expressed and contained within this framework.

Paula suggested that cancer may be caused by an injury to the breast, but stated she was uncertain how the disease developed. She sought explanations in religion, believing that the cancer was sent as a test of her faith, and to help family members realise how much she meant to them. She spoke, in the second interview, of the progressive fatal course of cancer. It is a "very dangerous sick, cancer is something, it goes further in your body". She explained in the third interview that temporary relief from pain was derived from prayer. "Die pastoor het vir my gebid. Hy het sy hande op my kop gelê en toe bid hulle vir my bors. En toe is my bors weer mooi stil". In her understanding the healing power of God and church is pitted against the force of the Devil.

> "En toe het ek hom bestraf. Ek het gesê Satan, in die naam van die Here jy wil hê ek moet ten gronde gaan ... maar ek sal vir jou wys. Die Here sal vir my gesond maak ... Ek vertrou en ek glo die Here gaan vir my gesond maak."

She attributed her recent injury to the workings of the Devil, a jealous and vengeful force. "Toe sit ek en dink, dit is nou regtig die Duiwel want die Duiwel is 'n jaloerse mens. Hy wil nie sien dat my bors moet gesond word nie." Survival is a personal victory against these odds.

Life struggles and illness

Paula was raised in District Six and moved to Elsie's River when she was 13 years old. She is the eldest of eight siblings. Her father worked as a driver, abused alcohol and died seven years ago of cancer of the stomach. Her mother was employed as a cleaner; she was described as a soft-hearted person who worries a lot. Paula was removed from school after Standard 3 so as to care for her younger siblings. She was first employed, aged 14 years, in a shoe factory after which she had several factory jobs until entering her present employment over four years ago. She was pregnant when she married at the age of 20. Her husband, a plumber, was described as a joking, likeable man who drinks periodically and then becomes short-tempered. He has been unemployed for extended periods. Several years ago he had two extra-marital affairs from which three children were born; he was required to pay maintenance for them, stretching the family's already limited finances. Paula indicated she had come to accept this. However she revealed that she does not confide in her husband and was initially reluctant to tell him she had cancer as she was concerned he would speak loosely about it while intoxicated and would be pessimistic about her chances of survival. She reported that she does not mix with her neighbours and spends most of her leisure time at home or at church. She regards her overcrowded and impoverished living conditions as her central life problem and hopes to move into a council house one day but has no specific plans to achieve this, given her persistent financial problems. She has had no serious illnesses in the past and consults a doctor in her neighbourhood when necessary.

Paula's stated philosophy is: "Waar daar hoop is, is daar lewe". During the third interview she spoke of her coping style: "Vir my is dit soos ek het nie die kwaal nie". She refuses to ruminate on it.

> "As ek nou miskien begin te worry het ... en ek gaan sit en ek sit en ek sit ... en my gedagtes sit ek nou op dié siek wat ek het ... As ek moet so gewees het dan sal ek mos 'down' gegaan het, ek sal ten gronde gegaan het."

She considers it important to be courageous and maintain her lively friendly manner "net soos altyd". She stated that she does not request extra assistance or share with her family the pain and difficulties she has experienced. She wishes to protect them from any negative consequences of her illness. She reiterated several times that her hope and faith have never faltered. "Ek het nog nooit een oomblik gevrees, vir dié siek wat ek het, vir dié kanker." She enjoys receiving compliments about her physical appearance: "Mens sal nooit sê dat ek het daai siek nie" (which may be contrasted with Cheryl's fear that a healthy appearance conceals disease).

Paula considered compliance with medical advice and treatment as crucial for her recovery.

> "Ek wil gesond wees. Ek kannie haastig wees as ek daar kom by die hospitaal of ontevrede wees omdat ek nou daar moet wees .... Jy moet doen wat hulle sê, want hoe kan jy gesond word as jy nie wil luister na wat hulle vir jou sê nie."

At the same time she viewed medical practitioners as working under Divine guidance and support. Medical treatment can remove the lump and stop the cancer from spreading, however religious belief invokes a greater healing power.

Paula's illness can be understood within the burdens and struggles of her daily life, framed by her life history and position as a 'coloured' working class woman. Her experiences find expression within a religious framework and are rooted in compliance with authority and in an attitude of resignation and acceptance.

ILLNESS NARRATIVE - Fatima D.

Fatima D. is a 58 year old Muslim woman living with her niece and family in a house in Retreat. She was widowed two years ago and has no children of her own. I saw Fatima on two occasions after which she departed on a year long overseas trip. Her niece informed me that she had been well since the mastectomy and was looking forward to her travels.

No longer benign

The significance of Fatima's breast lump was transformed over a period of 14 years. "I had this lump for years. It went and it comes and it went and it comes". She would forget about it for a while and then "all of a sudden it pops up again ... it was something difficult to understand because it comes and it goes". A friend advised that she have it checked "because it can be a serious matter". She did so several times and each medical examination revealed no cause for alarm. A few weeks prior to the first interview she became concerned as she felt pain in her breast and underarm and thought the lump was growing in size. As was the case with Paula, the meaning of the lump changed with this additional experience of pain; she told the doctor, "If it wasn't sore then I wouldn't have come to see you".

When a biopsy was performed Fatima imagined that this small operation was the only treatment she required and was confused by her referral to Groote Schuur for further tests and management. "I thought it wasn't a serious matter ... I thought it was now finished, nothing to worry about." On diagnosis, Fatima's symptom, previously always a 'benign breast lump' was transformed into 'breast cancer' and a mastectomy was advised. She expressed her confusion and shock at this diagnosis. She was distressed about the mastectomy but resigned to the doctors' treatment decision.

> "I feel it's not nice to have just one bust but never mind I'll have to cope with it. It's for my health ... I just take it as it comes, what can I do now? ... If they think it's the best way out then I have to do it their way you know. I won't grumble about it."

Past life experiences

Fatima was raised in Cape Town, the youngest of eight siblings. She was withdrawn from school after completing Standard 2 as her parents believed that further education was unnecessary. She was employed as a factory worker from the age of 13 until she married at 38 years of age and moved to Durban. She spoke of her husband, a bricklayer, as a gentle, lovable, and uncomplaining man and their marriage as generally happy. Fatima had three miscarriages after which she stopped trying to conceive, believing that it was God's will that she not bear children and that her infertility was due to a physical weakness which could not be understood or treated medically. She was devastated when her husband died of a myocardial infarction in 1987, and she returned to live in Cape Town in December 1988.

Fatima described herself as a worrier who likes her life to be orderly and under control. She enjoys being busy and active and seldom resorts to bedrest when sick. She rarely consults doctors believing this is only necessary for serious illness. Her husband and parents preferred the use of home remedies to formal medical services. In coping with this illness as with previous losses she has had to face (miscarriages, deaths of her parents, siblings and husband) Fatima has searched for meaning and found comfort within her religious faith. "If I must be sick I must be sick. It's the will of God." She makes a distinction between her cancerous breast lump and herself generally, as "never ever a sickly person". She presents herself as cheerful and optimistic: "I just take it the way it comes, I've got no worries and cares in the world". This attitude stands in contrast to the themes which underlie her explanatory model.

'An inside story' - explanations and emotions

Issues of responsibility, control and contamination are prominent in Fatima's explanations of her illness. She spoke of her understanding of cancer. "I think it's an inside story. Sometimes they say you can hurt your bust from outside too but I don't know, to me it's an inside story." She suggested that women who cannot bear children are more likely to suffer from breast cancer.

> "Most of the friends I have that's got a bust removed it's all people that hasn't got children ... If they can't bring children in the world maybe it's something that's affecting your bust because the first thing the doctor ask me is have you got children."

Several meanings may underlie this conceptualisation of an "inside sickness". Fatima associates the cancer with her infertility, which she has described as a physical problem with baffling mechanisms, an inherent weakness. This may reflect a sense of failure and feeling of responsibility for her condition. She experiences guilt at her possible negligence.

> "If somebody could've told me how it happens that you can get breast cancer, you know you could've been on the alert hey ... You could've looked more after your breast, and I wouldn't have let it go on for so long when I went to --- Hospital."

This theme of personal responsibility is reflected in a social responsibility regarding possible contamination of others. "As long as it's not going to touch the next party. It won't hey? It's not a thing that, it's not like a virus?" The metaphor of an 'inside story' is also related to her lack of control over the course of cancer, which spreads and "can affect my whole body". The image of internal and external contagion is striking in this account.

Fatima described a leg infection she had developed after her return from Mecca some years previously. She sought help from a Muslim healer as medical practitioners were unable to explain the nature of the problem or provide treatment. She contrasted this ailment with cancer which she said she regarded as a "medical case", for which spiritual healing was inappropriate. Fatima consented to medical treatment and expressed her trust in the knowledge and skills of doctors. At the same time she hinted at her doubts in this regard, linked to their previous inability to treat her infertility and leg problem and their possible failure to diagnose her breast cancer at an earlier stage: "I left it just like that because the doctors said there's nothing wrong". She believed that she has no option but to give medical doctors control over the process of healing. Thus Fatima's illness experience may be seen in the context of her prior losses and her religious faith, and in relation to her conceptualisations of medical complaints and health care systems.

ILLNESS NARRATIVE - Gertrude S.

Gertrude S. is a 73 year old Christian woman living with her daughter and son-in-law in a house in Lansdowne. She was widowed 13 years ago.

She is a small, frail-looking woman, her movements slowed and her hands swollen from arthritis. She sat rubbing her hands constantly in her lap, was subdued and soft-spoken. At our second meeting she interacted more easily in sharing her experiences with me. In the third interview she appeared tired and despondent and at times was tearful.

Confronting the symptoms

When Gertrude first felt a lump in her breast three months before the first interview she did not wish to assign it too much significance while it did not apparently interfere with her daily functioning. She had heard and read that, "when you got a lump in your breast it's cancer ... but then I sort of put it out of my mind, I don't want to think of cancer". At the same time: "I hear people say if you've got cancer your hair fall out and a whole lot of other things but my hair stay the same ... I couldn't believe it can be that, I thought perhaps it's just a lump that come in there". She stated her reasons for delaying seeking medical help. "I never really had pain or it worry me. It's only the time when I must have a bath or dress that I will feel it." She anticipated that the doctor would refer her to hospital and wanted to avoid this. After her return from a visit to her sister in Knysna she thought "It must be something wrong because it's growing". She told her daughter and daughter-in-law who instructed her to consult a doctor. On explaining to the doctor that she was hoping the lump would disappear if she ignored it, she was told that "things like that don't go away, you must see to it".

When given the diagnosis and advised to have a mastectomy, Gertrude was "quite stunned when the doctors say that ... a little bit down, thinking now why?". She felt guilty about not having sought medical attention earlier as she might have prevented surgery; now "one part of me must go".

> "It's something terrible to have a part of your body cut away .... I'll only have one breast, this part will be all flat here ... I think well a person can get bras and stuff, padded and so on. And then I'm not worried because I say I'm that age already, I mean it's not for me to worry about that any more ... say Patty's age [her daughter], and she has her breast now put off, she'll be feeling very awkward, she's married, her husband and so on."

In the second interview prior to the operation, Gertrude spoke of living with the disease. "The sooner you get over it, get done with it, the easier for yourself. Because now you always walk with it, even if you talk to people, you bath and everything, but deep down in you is that. You sit with that complaint." Her family and friends encouraged her to accept "whatever must be done". She was comforted by reminders that there were others in her position: "I feel more at ease ... if they went through it and they're fine, I believe and trust in my Lord also it will be alright then". In the third interview she claimed she had adapted to the loss of her breast, was used to wearing a prosthesis and felt no physical discomfort due to the operation.

Explanations of course and cure

Gertrude spoke (as did Fatima) of breast cancer as "an inside business". She had considered that a fall or injury might cause the disease, but added that noone could explain its aetiology. "Some lumps they say is not cancer, it's just a lump and there is some lumps that is cancer, it can be cured or the breast must be put off. It all depends how far it is." The course of cancer is progressive - it grows and spreads in stages through the body. Ultimately cancer can be fatal. Gertrude was apprehensive that the disease was hereditary and encouraged her daughter to examine her own breasts.

> "She must be careful ... because they say a woman, I did read it in the book, must have a checkup regularly by a doctor for breast cancer ... because now Patty is my daughter and I don't know if it will travel, you know what I mean, if it will affect her also."

Gertrude incorporated both spiritual and medical models in her search for understanding and cure. In the third interview she stated, "God perhaps works in a wonderful way; He got me this now because say I was maar well I would never had time to sit still and read His word and perhaps think of someone else that's not well". She felt strengthened by the support and healing prayers of members of the Assembly of God church which she attends. "He laid hands on me and prayed for me. I believe that when he prayed, it wasn't healed but it did stop growing ... so God's hand was in it." She also asserted her belief in obedience to the authority of the medical doctors who are socially designated as healers. "Even the Bible says that you must be obedient to those that have authority over us. The doctors and the nurses have authority over us to help us. So we must be obedient and do what they say."

Life and suffering

Gertrude is one of eight siblings and grew up in George. She regularly visits her sister and brother who are still resident there. She left school after completing Standard 4 and moved to Cape Town at the age of 20 when offered employment as a domestic worker. After working as such for several years she was employed as a factory worker until she was pensioned at the age of 60. She married at 33 years of age, has a married son and a daughter with whom she has been living for the past three years. Gertrude's husband, a lorry driver, was described as a soft-hearted man who drank too much. Thirteen years ago, after having suffered severe back pain for some time, he consulted a doctor and was diagnosed as having lung cancer; he died a month later. Gertrude struggled to adjust to his death and to cope on her own with practical and financial matters.

Gertrude's responses to her illness have incorporated characteristic patterns of obedience to authority, powerlessness to substantially alter her life and resignation to adversity. "It won't help if I fight against it and say no. I must just be satisfied with it, because it is there and it must come out, my breast must be removed." Her advice to other women with breast cancer is to "believe and trust that there is someone greater than even the doctors and nurses, someone greater that will do the work for you ... just trust and believe ... and don't give up hope".

Gertrude has suffered from arthritis for the past six years. She experiences a great deal of pain, tires easily and her movements and activities are severely restricted. She described herself as an undemanding, compromising person who avoids conflict: "I will now first watch, see how he takes things ... I'll adapt myself to that". She spoke of her concern about becoming an invalid and thereby burdening her daughter or causing conflict in her daughter's marital relationship. Gertrude focuses on ongoing pain and arthritis problems which she has found more handicapping than the breast cancer and mastectomy. "It's the arthritis that's keeping me back that I can't move around like I want to and do things as I used to do." At times she feels discouraged and downhearted about what she has to endure. She spoke of this.

> "I can maar go, the Lord can maar take me away because of the pain I have, but from my operation I really can't say that I suffer pain or discomfort ... Times that I really feel sick and down. Sometimes I cry here alone, I sit and cry my heart out ... if not for the pain in my leg then I feel much better."

Gertrude's illness is lived with an awareness of her old age and approaching death. The themes which pervade her experience are reflected in her narrative of suffering.

ILLNESS NARRATIVE - Ann D.

Ann D. is a 56 year old woman living with her husband and three children in a house which they own in Athlone.

During the first interview Ann appeared bewildered, responded briefly to questions and made little spontaneous conversation. For the second interview she welcomed me into her home, chatted and joked. She spoke openly but appeared more reluctant to discuss the cancer directly. When I saw her some months later, she was extremely friendly and talkative and indicated she had resumed her usual activities and was feeling generally content. She spoke in a confident, positive manner about her illness.

The meaning of the breast lump

Only two weeks passed from Ann's discovery of her breast lump (while bathing) to medical diagnosis. She examined her breasts weekly, having attended a talk at the church on early breast cancer detection. Her husband and friends from the bible group suggested she seek medical advice and encouraged her to think positively. She wondered if the lump could be a "gland", as "it wasn't sore and it never throbbed or nothing". She attended the Day Hospital hoping for a prescription for medication. On being referred to Groote Schuur she considered that it might be cancer. Ann spoke in the first interview of her feelings following diagnosis and decision to perform a mastectomy: "It was a shock for me; it's like death that came into our house". But she described it to her family as "a little cancer in the breast, a lump".

In the second interview Ann described the significance of the breast cancer.

> "I was sitting on the bed, before the doctors come. The bed was very high and my feet was now down. And I look and I said, rather that my breast be off not my feet or my arms or my eye that I can't see. That I can still walk about, I can still see and I can use my arms, doing something. My breast is now under my clothes, noone will see."

In the third interview she alluded to her difficulty in adjusting to the loss of her breast, to a prosthesis and to the physical discomfort. "I look down now and I feel, look now what happened to me." However she asserted, "I got my health back ... I get used to it; you've got to carry on like it wasn't there".

Illness explanation

Ann related her conceptions of breast cancer to past personal experience.

> "I was reading about it, if a mother don't breastfeed her babies, now my babies were all bottle babies. Now I don't get the, I don't know what you call it, the baby must now drink on you. Say the exercise inside your breast, where the milk comes from ... maybe there was always something, a clot, whatever's in your breast that came together after all these years. I thought that. It's worthwhile that the baby drinks on you, for your own health."

She stated that cancer begins with a lump which "sometimes is cancerous and sometimes it's not". Cancer spreads and progresses on a deteriorating path to death. It is important to diagnose and treat cancer early in its development, otherwise prognosis is poor. Ann asserted that it is important to believe in God's power, have faith in medical expertise and comply with medical treatment. She claimed that it is possible not to let cancer adversely affect one's lifestyle and routine; since the shock of the diagnosis, she has felt generally calm and composed.

The personal and social context of illness

Ann's illness experience is strongly influenced by her position within her social network. She has attempted to highlight the positive aspects of the experience and find value in it, in a manner typical of her approach to life in general.

Ann stated she could not recall any really difficult times in her life. She grew up in District Six and moved to Bonteheuwel in 1960. She is the youngest of three siblings one of whom died six years ago. She described her parents as "wonderful and homely". Her father died 15 years ago of 'old age' and she visits her ailing mother weekly. Ann attended school until Standard 6 after which she worked in a factory as a machinist for approximately 15 years. She left her job when she married at the age of 31. She described her marriage of 25 years as "wonderful". Her husband is a builder, currently in temporary employment. He was described as a supportive and quiet man who enjoys gardening. They have two sons and a daughter. She enjoys knitting and reading and is a regular attender at Anglican Church services, Bible study groups and women's meetings. She has not suffered a serious illness until this point.

Ann said she is regarded as friendly and gregarious. She portrayed herself as a strong coping person on whom others rely. She has attempted to maintain this during her illness. It has thus been important for her to continue to evaluate herself as active and healthy and in some ways to shield family and friends from the seriousness of her illness. She copes by "just taking it away out of my mind" and tries not to worry as this would exacerbate her condition. "I mean it happened now ... I can't do anything now. Otherwise I'll make myself sick ... from worrying or so, or depressed, you make yourself sick." This is consistent with her motto: "What will be will be, sera sera, whatever will be".

In the third interview Ann stated that she feels gratified when complimented on her healthy appearance. After the operation visitors could not believe "I looked like that, so happy and radiant". She added that people have been saying "Ooh Ann you look so nice you would never never say you had such a big op". This includes the doctors. "They're very friendly ... they're happy about your progressing. You're not sick and you don't complain, you can see that also, they like that." She asserted that her routine has not been severely disrupted as she has not experienced much pain. Ann has not let the breast cancer define her as "chronically ill" and considers her period of ill-health to be over. "I'm healthy and ... I go like I used to go. I've never been sick. I never had a pain or so, nothing." It is evident that this cheerful manner and coping style were reproduced in Ann's interaction with me.

Ann's illness experience has in part had a positive impact on her life. This has been due to the support and assistance offered by her strong social network, compliments and attention ("I had a lot of visitors ... and the flowers was all over and that made me happy") and chance to prove her courage and strength of character. In addition the operation afforded her an opportunity to escape from her daily routine and responsibility. She said, "Now I'm excited to be in hospital ... and sleeping in a hospital for the first night, in a nice bed with the white ceiling". She has developed new social contacts as she has become friendly with two women she met in the hospital and attends Reach for Recovery meetings.

Ann and her friends discuss and share their illness experiences. She enjoys relating her story and hearing those of other women. "I talk, when we come to [church] meetings and sit together. People talk to me about their sickness, what happened to them and I also come out with my story." She has accepted this illness as a challenge and has attempted to minimise the negative consequences and to reassert control over her life. Furthermore Ann has always nurtured and supported others, particularly those who are elderly and ill. Her experience of breast cancer may be seen to have expanded her life experience and thereby her 'qualifications' for this position.

CULTURAL MEANINGS OF BREAST CANCER

This level of illness meaning incorporates the cultural metaphors and symbols contained in cancer patients' experiences. Many themes echo those referred to by Kleinman (1988b) and Sontag (1977). The patients are forced to confront fears associated with images of the disease and are regarded as bearers of these symbols (Kleinman, 1988b).

Interview material alluded to the image of cancer as a disease of growth and spreading, an invasion of space (Sontag, 1977): "touch of cancer, beginning of cancer"; "it spreads through my whole body"; "it's something that grows"; "it can affect my whole body"; "dit kan verder gaan"; "grow grow and get big"; "dit vreet verder".

Cancer evokes images of pollution and contamination. For example Cheryl stated: "It wasn't that far and ... the gland wasn't touched on, my glands was still clean". The spreading within is mirrored by external contagion in Fatima's concern: "As long as it's not going to touch the next party. It won't hey? ... it's not like a virus?".

Cancer defies modern technological solutions and is a reminder of human vulnerability. It is regarded as a pervasive disease of our times. In a strange inversion, Cheryl depicted the cancer victim as fortunate to have had the hidden disease revealed; she recounted what her sister had told her. "Everybody got cancer, we're all born with cancer but we just don't know where. You are lucky if it's shown out early. The doctors can still fix it or do something about it."

Cancer conjures up images of a toxic environment; it is most powerfully perceived as a disease of industrialised society. Fatima contrasted 'modern' diets and lifestyle with a healthier past.

> "It's modern times, we're in a modern environment. And my husband always used to tell me, he said, in former days the people never used to eat chicken that don't see the sun .... Nowadays they got tin vegetables, frozen this, frozen that, that causes - you see people are too much sickly nowadays. In former days the people wasn't so sickly. I don't know. People used to get old and have a lot of children those days."

The salience of breast cancer relates in part to issues of body image and sexuality. Cheryl framed the illness as a continuation of women's suffering generally, for example during pregnancy and childbirth. She expressed her fear of the disfiguring surgery and its threat to her sexual attractiveness. She spoke too of her ambivalence regarding mastectomy; while it possibly offered one a better prognosis, the cost involved was great. Thus breast cancer was preferable to other cancers as "they can remove your breast and it won't go further ... and you can still have a normal life". But at the same time: "It was horrible at first because I thought I'm going to lose my breast - what is my husband going to say about it ... and now where is the child going to drink from?". Ann asserted that the disfigurement due to mastectomy could be concealed and did not involve loss of mobility or imply disability; it was thus preferable to amputations of other parts of the body. In contrast Paula said: "'n Vrou se bors is baie belangrik, kyk, 'n oog, en 'n mens se tong, en 'n mens se bors ... dis die belangrikste dele van 'n mens se liggaam". Ann conveyed her surprise that wealthy slim women (as encountered in her group meetings) are also subject to the pain of mastectomy. "There are high, rich people ... they look so smart. Ooh, I couldn't believe it ... you won't say it on their faces. You'd never think it's people that had this - smart, small-busted."

In that it is fearful and lethal, the disease is associated with shame and the sick person may be stigmatised. It may be experienced as a sign of personal weakness or failure. Paula's mother instructed her to keep the diagnosis secret from all but the closest family. Cheryl anticipated that people would predict her untimely death, and pity her. Repeating the image of contamination she commented graphically on society's fear of the disease: "Our mind is poisoned with cancer, you're going to die if you've got this cancer or that cancer". She also spoke of her fear of being seen as different and thereby 'abnormal'; she felt defiantly pleased when a friend rebuked a colleague who had commented on Cheryl having the disease: "But she hasn't got cancer, she's as normal as any of us!".

The ill person may have resources to transform some of the cultural meanings. In this regard the positive aspects of Ann's illness have been discussed above, in relation to her social network and personal qualities. In addition the illness experience is mediated by gender, 'race' and social class. Financial resources, availability of material comforts, opportunities for leisure and accessibility of services all impact on the way the illness is lived by the individual woman. Similarly a woman's role within the family and perceived responsibilities as wife or mother involves certain demands which contribute to her experience. Ann, for example, protects her family: "There's a little cancer in the breast". Clearly age is also a significant factor. It was shown how Gertrude's feelings about mastectomy and the perceived danger of the disease were shaped by her everyday experience of old age (arthritic pain, lack of mobility and altered perception of her sexuality and of death).

Kleinman (1988b) argues that the suffering of the afflicted person leads to the existential questions of 'why me?' (bafflement) and 'what can be done?' (order and control). These women turned to health professionals for expert assistance, but the medical perspective could not provide adequate explanations or completely satisfy their need to control the illness. Religious and spiritual symbols provided a framework to deal with these issues. In addition the explanations and solutions offered by the social network were extremely important. Popular remedies were also used, for example Paula followed the advice of older friends and family, by eating yoghurt, and applying a cabbage leaf rubbed with olive oil to her breast.

Lay theories of illness causation may identify the source of the problem in either the patient himself/herself, in the natural world, the social world or the supernatural world. The patient's responsibility for illness may be seen to lie in diet, injury, careless or other behaviour, or be seen as outside of conscious control, for example in his/her personality traits or patterns of responding (Helman, 1984). Ideas about the mechanisms of the disease may be differentiated from explanations for the illness. In these interviews the illness was sometimes attributed to 'God's will'. At other times reasons were sought in past experience, or in personal failings. The issue of personal responsibility for detection of the cancer and appropriate action was raised. Cheryl said, "If you don't take notice, it could kill you" and "It is curable but it just depends on you person[ally], if you go for your treatment regularly". Fatima felt concerned about medical failure to recognise the disease and guilty about her own possible negligence: "You know you could've been on the alert ... looked more after your breast".

The narratives of Paula and Gertrude were woven with spiritual images of disease and healing. Anxiety may be reduced and a sense of control derived through such symbols and rituals. An image of breast cancer as an "inside story" has connotations of disease as an expression of the inner self. The path to recovery has been viewed as a battle of body and mind/spirit. The need to respond positively to the crisis and thereby find value in the experience involves a test of moral strength. While the women spoke of their belief in seeking biomedical solutions, they also advocated a positive attitude and strong will as crucial for survival. Excessive worry or loss of hope could exacerbate the illness. This conceptualisation enabled them to feel they were actively involved in confronting and resolving their condition.

These culturally based illness meanings envelop the cancer 'sufferer'. The lived experience of breast cancer is influenced by such themes, within personal and social worlds. The stories of the five women testify to this.

CONCLUSION

This dissertation has explored aspects of illness and health care with specific reference to women's experience of breast cancer. It has outlined an hermeneutically-oriented medical anthropological approach to studying illness. This views illness as a meaningful experience of the individual.

It has been argued that patients' explanations of illness are constructed and transformed in an ongoing way in relation to personal and social factors as well as biological processes. Cancer has particular cultural salience in twentieth century Western society (Sontag, 1977). Emotionally-charged images of the disease and the afflicted person are created. The biomedical model has been criticised for attending insufficiently to patients' illness experiences and the personal and social contexts of sickness, thus potentially leading to patient care problems. Discrepancies between the explanatory models of patients and medical practitioners may result in unsatisfactory therapeutic interventions (Kleinman, 1978a; Good & Good, 1980).

A selective review of the literature on psychosocial aspects of breast cancer has been presented. Numerous psychological studies have investigated the reasons for delay in presentation for medical treatment following onset of breast symptoms. Research has also focused extensively on the psychological impact of mastectomy. This work has implications for the planning of therapeutic interventions, and for popular and professional understandings of women's responses to breast cancer. Many of the empirical studies may be criticised for fragmenting breast cancer experiences and separating them from their meaning within the person's daily life. The social nature of emotional responses may be obscured (see Rosser, 1981).

This study has offered an additional perspective on the breast cancer experience by using medical anthropological insights and by applying Kleinman's analytical framework to explore 'illness narratives' (1988b). It has discussed the 'inside stories' of five women and focused on the meaning of the symptoms, medical diagnosis, explanations of the disease and the significance of the illness within personal and social contexts. This has included a consideration of the cultural meanings of cancer. It is suggested that the theoretical framework was able to provide coherence to the interview data, reveal the richness of the material and elucidate key issues and themes.

The interview material demonstrated that, from the time of discovery of the breast symptoms, the experience was a social one. Distress was signalled by the significance of a breast lump or the experience of pain. Symptoms were evaluated, communicated and shared within a social setting. The women's responses, decisions and actions were influenced by these interactions. The advice of family and friends as well as ongoing concern about the symptoms over a period of time, led them to seek medical help. They were also influenced by the extent to which symptoms interfered with their daily functioning. For some of the women this process involved a period of 'delay' prior to consultation with a doctor. Transformation of the experience followed the diagnosis of breast cancer, as part of becoming a 'breast cancer patient'.

The women's explanatory models were explored during the interviews. Cancer was seen as a mysterious disease, a disease of growth, spreading and contagion occurring 'inside' the body. Explanations were formulated within social and cultural contexts, including the influence of medical encounters. Various illness explanations operated simultaneously and were given expression within the women's lives.

The issues of disfigurement and disturbance of body image were mentioned; however the women did not focus exclusively on the significance of the breast. While fear of mastectomy was expressed, other general fears relating to cancer, recurrence of the disease and death were also prominent. The social stigma and shame of illness were another concern. This was reflected in anxiety about being different or disabled. A recurrent theme in the interviews was that of personal responsibility for causation and outcome of the disease. A further issue related to control and order of the experience (particularly given the ongoing uncertainty of prognosis). The women's illness experiences were shaped within the personal and social domains, for example by a need to appear strong, an intolerance of weakness, a life history of hardship and struggle, an attitude of resignation, etc. Material circumstances, class position, gender and age were also implicated in the varied experiences of these women. The interview material revealed to some extent the changing nature of explanations and responses over the course of the illness. Inconsistencies in an account did not imply contradictions in the data which should be avoided but rather reflected ambivalence and change in the woman's own emotions and understandings.

It was evident from the women's accounts that health care and healing go beyond professional medical help. Their social networks, popular remedies and lay helping relationships were important aspects of the illness experience. Meaning was frequently sought within a spiritual framework; coping resources and support were also derived through faith and the social aspects of religious involvement. The women felt encouraged and reassured by social comparisons, either with other women who were less fortunate or with women who in fact had survived and coped well. They asserted their belief in and dependence on medical treatment although some doubts were expressed by two of the women. Kaufman (1988) has noted that patients hold assumptions and expectations of the power of biomedical interventions to heal, control and order sickness. Both doctors and patients generally believe that doctors should be the ones to make treatment and other medical decisions (Fisher, 1988). This was evident in the women's perceptions of medical treatment and in their acceptance of professional authority.

It has been shown that the impact of breast cancer may not be all negative; it may in part present constructive opportunities for the sick person. In addition resolution of life crises generally occurs through the resources of the individual and his/her social networks. Thus women with breast cancer will not necessarily require professional psychological treatment. They may not perceive that they have problems requiring intervention or may not conceptualise or express their problems in the same way as potential 'helpers'.

Kleinman (1988b) has argued that a meaning-centred model has relevance for medical practice. Therapeutic benefit may derive from allowing the patient to speak about her experiences within the details of her life history and from 'empathic witnessing' of the story. Interpretation of the illness narrative may be used to highlight illness complaints, prioritise adverse consequences of the illness and plan appropriate therapeutic interventions. Particularly in chronic illnesses cure may be impossible; the goal is to limit disability by dealing with the life problems caused by the disorder. The method of understanding illness as discussed in this dissertation may be utilised by clinicians to support, counsel and assist patients and to deal with psychosocial problems. This approach complements ongoing management of the physical symptoms. Practising clinicians may respond that it is impractical, given the responsibilities and demands of large caseloads and complex management issues. However it is suggested that more effective therapeutic interventions and better patient care may result from such an approach to illness.

Kleinman's framework has been criticised for inadequately incorporating issues of power. In this regard the social and political processes implicated in the negotiation and interpretation of narratives (with family, friends, doctors, and researchers) is a crucial issue (Kirmayer, 1989). An additional point is that Kleinman does not articulate one distinct psychological or social theory and the processes linking the various layers of meaning are unclear. Nevertheless it is believed that his model is useful in that it delineates various illness meanings none of which are trivialised or conceptualised as static entities 'imposed' on the illness. It locates illness and suffering within personal and social contexts and elucidates how illness is transformed and made meaningful within broader life themes, including the influence of clinical settings.

A limitation of the present study was the timing of the initial interview which was soon after diagnosis, arguably a traumatic, confusing period for the women, when the illness experience may have been relatively 'inaccessible' for discussion. However it was thought to be important to interview the women prior to the start of treatment and choice of timing and setting of the interviews was constrained. This problem was addressed to some extent by conducting the second interview in the woman's home, and a follow-up interview some months later. It was thus possible to gain a perspective on a more extended period of the ongoing illness experience. Given the limited time spent with each woman, a further problem lay in developing a trusting relationship with her which would facilitate open discussion. In addition the interview situation demanded of participants that they reflect on their illness in a particular way. The manner in which they spoke about their experiences would have been influenced by this expectation, and by my effect on them (questions asked, verbal and non-verbal cues and responses, their views of me).

What direction might one take in future research? It is believed that the impact of breast cancer on the woman's family, and on other close relationships, is crucial; studies might usefully examine their involvement in the breast cancer experience. Further insight might be gained by conducting regular interviews with women over the course of a few months, in an open-ended way, so as to record changes in narratives over time. Another avenue of exploring women's experiences of breast cancer would be to hold discussions with a group of women; this might evolve into a therapeutic intervention if the women so desired. It would also be informative and clinically useful to conduct a detailed exploration of the doctor-breast cancer patient interaction, including the exchange of information and of models of understanding.

It is believed that, despite its limited scope, the present study has contributed to an understanding of the impact of breast cancer. The insights which have been offered may be used to interpret the illness experience of women suffering from the disease and thereby enhance the therapeutic aspect of patient care.

REFERENCES

Ahmed, P. (Ed.). (1981). **Living and dying with cancer**. New York: Elsevier.

Aiken, L.H., & Mechanic, D. (Eds.). (1987). **Applications of social science to clinical medicine and health policy**. New Brunswick: Rutgers University Press.

Antaki, C. (1988). Explanations, communication and social cognition. In C. Antaki (Ed.), **Analysing everyday explanation: A casebook of methods** (pp. 1-14). London: Sage.

Armstrong, D. (1987). Theoretical tensions in biopsychosocial medicine. **Social Science and Medicine, 25**, 1213-1218.

Baer, H.A., Singer, M., & Johnsen, J.H. (1986). Toward a critical medical anthropology. **Social Science and Medicine, 23**, 95-98.

Baider, L., & Sarell, M. (1983). Perceptions and causal attributions of Israeli women with breast cancer concerning their illness: The effects of ethnicity and religiosity. **Psychotherapy and Psychosomatics, 39**, 136-143.

Baider, L.A., & De-Nour, A. Kaplan (1988). Breast cancer: A family affair. In C.L. Cooper (Ed.), **Stress and breast cancer** (pp. 155-170). Chichester: John Wiley.

Bard, M., & Sutherland, A.M. (1955). Psychological impact of cancer and its treatment: IV. Adaptation to radical mastectomy. **Cancer, 8**, 656-672.

Bartelink, H., Van Dam, F., & Van Dongen, J. (1985). Psychological effects of breast conserving therapy in comparison with radical mastectomy. **International Journal of Radiation Oncology Biology Physics, 11**, 381-385.

Battersby, C. (1981). Psychological implications of mastectomy. **Australian and New Zealand Journal of Surgery, 51**, 300-303.

Beckmann, J., Blichert-Toft, M., & Johansen, L. (1983). Psychological effects of mastectomy. **Danish Medical Bulletin, 30**(Suppl. 2), 7-10.

Beckmann, J., Johansen, L., Richardt, C., & Blichert-Toft, M. (1983). Psychological reactions in younger women operated on for breast cancer. **Danish Medical Bulletin, 30**(Suppl. 2), 10-13.

Berg, D.N., & Smith, K.K. (Eds.). (1985). **Exploring clinical methods for social research**. Beverly Hills: Sage.

Bloom, J.R. (1981). Cancer care providers and the medical care system: Facilitators or inhibitors of patient coping responses? In P. Ahmed (Ed.), **Living and dying with cancer** (pp. 253-272). New York: Elsevier.

Bloom, J.R. (1982). Social support systems and cancer: A conceptual view. In J. Cohen, J.W. Cullen, & L.R. Martin (Eds.), **Psychosocial aspects of cancer** (pp. 129-150). New York: Raven Press.

Blumberg, B.D., Ahmed, P., Flaherty, M., Lewis, J., & Shea, J. (1981). Living with cancer: An overview. In P. Ahmed (Ed.), **Living and dying with cancer** (pp. 3-35). New York: Elsevier.

Blumhagen, D. (1982). The meaning of hyper-tension. In N.J. Chrisman & T.W. Maretzki (Eds.), **Clinically applied anthropology: Anthropologists in health science settings** (pp. 297-323). Dordrecht: D. Reidel.

Boonzaier, E. (1988). Understanding disease: Are 'first world' and 'third world' patients fundamentally different? **South African Family Practice, 9**, 454-457.

Calnan, M. (1984). The health belief model and participation in programmes for the early detection of breast cancer: A comparative analysis. **Social Science and Medicine, 19**, 823-830.

Calnan, M., & Rutter, D.R. (1988). Do health beliefs predict health behaviour? A follow-up analysis of breast self-examination. **Social Science and Medicine, 26**, 463-465.

Cameron, A. & Hinton, J. (1968). Delay in seeking treatment for mammary tumors. **Cancer, 21**, 1121-1126.

Cape Provincial Administration (CPA) (n.d.). **Groote Schuur Hospital 50th Anniversary Annual Report 1987/88**. Cape Town: CPA.

Champion, V.L. (1985). Use of the health belief model in determining frequency of breast self-examination. **Research in Nursing and Health, 8**, 373-379.

Charlson, M.E. (1985). Delay in the treatment of carcinoma of the breast. **Surgery, Gynecology and Obstetrics, 160**, 393-399.

Chrisman, N.J., & Maretzki, T.W. (1982). Anthropology in health science settings. In N.J. Chrisman & T.W. Maretzki (Eds.), **Clinically applied anthropology: Anthropologists in health science settings** (pp. 1-31). Dordrecht: D. Reidel.

Cohen, J., Cullen, J.W., & Martin, L.R. (Eds.). (1982). **Psychosocial aspects of cancer**. New York: Raven Press.

Cooper, C.L. (Ed.). (1988). **Stress and breast cancer**. Chichester: John Wiley.

Csordas, T.J. (1988). The conceptual status of hegemony and critique in medical anthropology. **Medical Anthropology Quarterly, 2**, 416-421.

Cullen, J.W., Fox, B.H., & Isom, R.N. (Eds.). (1976). **Cancer: The behavioral dimensions**. New York: Raven Press.

Dent, D.M., & Hacking, E.A. (1983). New directions in the management of early breast cancer [Editorial]. **South African Medical Journal, 63**, 301-302.

Dent, D.M., Hacking, E.A., Wilkie, W., & Kottler, R.E. (1984). The management of breast disease in general practice. **South African Journal of Continuing Medical Education, 2**, 13-18.

Ehrenreich, B., & English, D. (1973). **Complaints and disorders: The sexual politics of sickness**. London: Writers and Readers Publishing Cooperative.

Eisenberg, L. (1977). Disease and illness: Distinctions between professional and popular ideas of sickness. **Culture, Medicine and Psychiatry, 1**, 9-23.

Eisenberg, L., & Kleinman, A. (Eds.). (1980). **The relevance of social science for medicine**. Dordrecht: D. Reidel.

Ellis, H. (1987). The treatment of breast cancer: A study in evolution. **Annals of the Royal College of Surgeons of England, 69**, 212-215.

Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. **Science, 196**, 129-136.

Estroff, S.E. (1988). Whose hegemony? A critical commentary on critical medical anthropology. **Medical Anthropology Quarterly, 2**, 421-426.

Fisher, E.R. (1989). Impact of pathology on the concept of conservative surgery. In H.H. Bohmert, H.P. Leis, & I.T. Jackson (Eds.), **Breast cancer: Conservative and reconstructive surgery** (pp. 24-28). Stuttgart: Georg Thieme Verlag.

Fisher, S. (1988). **In the patient's best interest: Women and the politics of medical decisions**. New Brunswick: Rutgers University Press.

Forester, B., Kornfeld, D.S., & Fleiss, J.L. (1985). Psychotherapy during radiotherapy: Effects on emotional and physical distress. **American Journal of Psychiatry, 142**, 22-27.

Freeman, H.P., & Wasfie, T.J. (1989). Cancer of the breast in poor black women. **Cancer, 63**, 2562-2569.

Freidenbergs, I., Gordon, W., Hibbard, M., Levine, L., Wolf, C., & Diller, L. (1982). Psychosocial aspects of living with cancer: A review of the literature. **International Journal of Psychiatry in Medicine, 11**, 303-329.

Gaines, A.D., & Hahn, R.A. (1985). Among the physicians: Encounter, exchange and transformation. In R.A. Hahn & A.D. Gaines (Eds.), **Physicians of Western medicine: Anthropological approaches to theory and practice** (pp. 3-21). Dordrecht: D. Reidel.

Gerard, D.M. (1983). Thirty year review: Mastectomy and sexual functioning. **British Journal of Sexual Medicine, 10**, 22-23.

Gergen, M.M. (1988). Narrative structures in social explanation. In C. Antaki (Ed.), **Analysing everyday explanation: A casebook of methods** (pp. 94-112). London: Sage.

Gifford, S.M. (1986). The meaning of lumps: A case study of the ambiguities of risk. In C.R. Janes, R. Stall, & S.M. Gifford (Eds.), **Anthropology and epidemiology: Interdisciplinary approaches to the study of health and disease** (pp. 213-246). Dordrecht: D. Reidel.

Gilman, S.L. (1988). **Disease and representation: Images of illness from madness to AIDS**. Ithaca: Cornell University Press.

Golden, M. (1983). Female sexuality and crisis of mastectomy. **Danish Medical Bulletin, 30**(Suppl. 2), 13-16.

Goldstein, D.A., & Antoni, M.H. (1989). The distribution of repressive coping styles among non-metastatic and metastatic breast cancer patients as compared to non-cancer patients. **Psychology and Health, 3**, 245-258.

Good, B. (1986). Explanatory models and care-seeking: A critical account. In S. McHugh & T.M. Vallis (Eds.), **Illness behavior: A multidisciplinary model** (pp. 161-172). New York: Plenum Press.

Good, B.J., & Good, M.-J. DelVecchio (1980). The meaning of symptoms: A cultural hermeneutic model for clinical practice. In L. Eisenberg & A. Kleinman (Eds.), **The relevance of social science for medicine** (pp. 165-196). Dordrecht: D. Reidel.

Gottlieb, N. (1987). Women's health and health care. In D.S. Burden & N. Gottlieb (Eds.), **The woman client: Providing human services in a changing world** (pp. 131-145). New York: Tavistock.

Graham, H. (1985). Providers, negotiators, and mediators: Women as the hidden carers. In E. Lewin & V. Olesen (Eds.), **Women, health, and healing: Toward a new perspective** (pp. 25-52). New York: Tavistock.

Greer, S. (1974). Psychological aspects: Delay in the treatment of breast cancer. **Proceedings of the Royal Society of Medicine, 67**, 470-473.

Greer, S. (1985). Cancer: Psychiatric aspects. In K. Granville-Grossman (Ed.), **Recent advances in clinical psychiatry** no. 5 (pp. 87-101). Edinburgh: Churchill Livingstone.

Greer, S., & Morris, T. (1978). The study of psychological factors in breast cancer: Problems of method. **Social Science and Medicine, 12**, 129-134.

Gregorio, D.I., Cummings, K.M., & Michalek, A. (1983). Delay, stage of disease, and survival among white and black women with breast cancer. **American Journal of Public Health, 73**, 590-593.

Gross, J. (1989). Emotional expression in cancer onset and progression. **Social Science and Medicine, 28**, 1239-1248.

Gudgeon, A. (1988). Can breast cancer be prevented? **South African Journal of Continuing Medical Education, 6**, 25-28.

Gyllensköld, K. (1982). **Breast cancer: The psychological effects of the disease and its treatment.** London: Tavistock.

Hacking, A., Gudgeon, A., & Lubelwana, K. (1988). Breast cancer in Xhosa women: A management challenge. **South African Journal of Continuing Medical Education, 6**, 57-62.

Hacking, E.A., Dent, D.M., & Gudgeon, C.A. (1984). Malignant tumours of the breast: Frequency distribution by age, race and stage at Groote Schuur Hospital, Cape Town, 1971-1981. **South African Medical Journal, 65**, 323-324.

Hahn, R.A., & Gaines, A.D. (Eds.). (1985). **Physicians of Western medicine: Anthropological approaches to theory and practice.** Dordrecht: D. Reidel.

Hales, R. (1986). **Psychosocial aspects of mastectomy: Crisis intervention as an efficient method of counselling.** Unpublished master's dissertation, University of Cape Town, Cape Town.

Helman, C. (1984). **Culture, health and illness.** Bristol: John Wright.

Hu, D.-S., & Silberfarb, P.M. (1988). Psychological factors: Do they influence breast cancer? In C.L. Cooper (Ed.), **Stress and breast cancer** (pp. 27-62). Chichester: John Wiley.

Hughes, J. (1987). **Cancer and emotion.** Chichester: John Wiley.

Hunt, L.M., Jordan, B., & Irwin, S. (1989). Views of what's wrong: Diagnosis and patients' concepts of illness. **Social Science and Medicine, 28**, 945-956.

Hunt, L.M., Jordan, B., Irwin, S., & Browner, C.H. (1989). Compliance and the patient's perspective: Controlling symptoms in everyday life. **Culture, Medicine and Psychiatry, 13**, 315-334.

Jamison, K.R., Wellisch, D.K., & Pasnau, R.O. (1978). Psychosocial aspects of mastectomy: I. The woman's perspective. **American Journal of Psychiatry, 135**, 432-436.

Kaufman, S.R. (1988). Toward a phenomenology of boundaries in medicine: Chronic illness experience in the case of stroke. **Medical Anthropology Quarterly, 2**, 338-354.

Kirmayer, L.J. (1989). [Review of **The illness narratives: Suffering, healing and the human condition**]. **Transcultural Psychiatric Research Review, 26**, 202-204.

Kleinman, A. (1978a). Clinical relevance of anthropological and cross-cultural research: Concepts and strategies. **American Journal of Psychiatry, 135**, 427-431.

Kleinman, A. (1978b). Concepts and a model for the comparison of medical systems as cultural systems. **Social Science and Medicine, 12**, 85-93.

Kleinman, A. (1980). **Patients and healers in the context of culture**. Berkeley: University of California Press.

Kleinman, A. (1986). Illness meanings and illness behaviour. In S. McHugh & T.M. Vallis (Eds.), **Illness behavior: A multidisciplinary model** (pp. 149-160). New York: Plenum Press.

Kleinman, A. (1987). Anthropology and psychiatry: The role of culture in cross-cultural research on illness. **British Journal of Psychiatry, 151**, 447-454.

Kleinman, A. (1988a). **Rethinking psychiatry: From cultural category to personal experience**. New York: Free Press.

Kleinman, A. (1988b). **The illness narratives: Suffering, healing, and the human condition**. New York: Basic Books.

Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. **Annals of Internal Medicine, 88**, 251-258.

Lang, G.C. (1989). 'Making sense' about diabetes: Dakota narratives of illness. **Medical Anthropology, 11**, 305-327.

Lauver, D., & Angerame, M. (1988). Development of a questionnaire to measure beliefs and attitudes about breast self-examination. **Cancer Nursing, 11**, 51-57.

Lehmann, A., Lederberg, M., Glicenstein, M., Lé, M., Sarrazin, D., Barreau-Pouhaer, L., & Petit, J.Y. (1989). Conservative treatment versus mastectomy with reconstruction in breast cancer: psychological effects. In H.H. Bohmert, H.P. Leis, & I.T. Jackson (Eds.), **Breast cancer: Conservative and reconstructive surgery** (pp. 414-419). Stuttgart: Georg Thieme Verlag.

Leis, H.P. (1989a). Epidemiology of breast cancer. In H.H. Bohmert, H.P. Leis, & I.T. Jackson (Eds.), **Breast cancer: Conservative and reconstructive surgery** (pp. 3-5). Stuttgart: Georg Thieme Verlag.

Leis, H.P. (1989b). Prognosis of breast cancer. In H.H. Bohmert, H.P. Leis, & I.T. Jackson (Eds.), **Breast cancer: Conservative and reconstructive surgery** (pp. 6-9). Stuttgart: Georg Thieme Verlag.

Lewis, F.M., & Bloom, J.R. (1978). Psychosocial adjustment to breast cancer: A review of selected literature. **International Journal of Psychiatry in Medicine, 9**, 1-17.

Littlewood, R. (1990). From categories to contexts: A decade of the 'new cross-cultural psychiatry'. **British Journal of Psychiatry, 156**, 308-327.

Lock, M., & Gordon, D. (Eds.). (1988). **Biomedicine examined.** Dordrecht: Kluwer.

MacArthur, C., & Smith, A. (1981, March 14). Delay in breast cancer and the nature of presenting symptoms. **The Lancet**, 601-603.

Magarey, C.J. (1988). Aspects of the psychological management of breast cancer. **Medical Journal of Australia, 148**, 239-242.

Maguire, G.P., Lee, E.G., Bevington, D.J., Küchemann, C.S., Crabtree, R.J., & Cornell, C.E. (1978). Psychiatric problems in the first year after mastectomy. **British Medical Journal, 1**, 963-965.

Maguire, P., Brooke, M., Tait, A., Thomas, C., & Sellwood, R. (1983). The effect of counselling on physical disability and social recovery after mastectomy. **Clinical Oncology, 9**, 319-324.

Marshall, J., & Graham, S. (1987). Cancer. In L.H. Aiken & D. Mechanic (Eds.), **Applications of social science to clinical medicine and health policy** (pp. 157-174). New Brunswick: Rutgers University Press.

McHugh, S., & Vallis, T.M. (Eds.). (1986). **Illness behavior: A multidisciplinary model**. New York: Plenum Press.

McKinlay, J.B. (1973). Social networks, lay consultation and help-seeking behavior. **Social Forces, 51**, 275-292.

McKinlay, J.B. (1980). Social network influences on morbid episodes and the career of help seeking. In L. Eisenberg & A. Kleinman (Eds.), **The relevance of social science for medicine** (pp. 77-107). Dordrecht: D. Reidel.

McLellan, G.L. (1988). Screening and early diagnosis of breast cancer. **Journal of Family Practice, 26**, 561-568.

Mechanic, D. (1986). Illness behaviour: An overview. In S. McHugh & T.M. Vallis (Eds.), **Illness behavior: A multidisciplinary model** (pp. 101-109). New York: Plenum Press.

Miller, T., & Swartz, L. (1990). Clinical psychology in general hospital settings: Issues in interprofessional relationships. **Professional Psychology: Research and Practice, 21**, 48-53.

Mishler, E.G. (1986). **Research interviewing: Context and narrative.** Cambridge: Harvard University Press.

Morris, T. (1983). Psychosocial aspects of breast cancer: A review. **European Journal of Cancer and Clinical Oncology, 19**, 1725-1733.

National Cancer Association of South Africa (NCA) (1988). **National Cancer Registry of South Africa 1986**. Cape Town: NCA.

Nel, C.J.C., Roode, F., & De Wet, J.I. (1985). The attitude of South African women to mastectomy for breast cancer. **South African Medical Journal, 67**, 728-729. X 6

Neuling, S.J., & Winefield, H.R. (1988). Social support and recovery after surgery for breast cancer: Frequency and correlates of supportive behaviours by family, friends and surgeon. **Social Science and Medicine, 27**, 385-392.

Nichols, S., Waters, W.E., Fraser, J.D., Wheeller, M.J., & Ingham, S.K. (1981). Delay in the presentation of breast symptoms for consultant investigation. **Community Medicine**, 3, 217-225.

Oakley, A. (1987). From walking wombs to test-tube babies. In M. Stanworth (Ed.), **Reproductive technologies: Gender, motherhood and medicine** (pp. 36-56). Cambridge: Polity Press.

O'Hare, P.A., & Wissing, M.P. (1988). The psychosocial implications of mastectomy for married women and their spouses. **South African Journal of Psychology, 18**, 129-135.

Olesen, V., & Lewin, E. (1985). Women, health, and healing: A theoretical introduction. In E. Lewin & V. Olesen (Eds.), **Women, health, and healing: Toward a new perspective** (pp. 1-24). New York: Tavistock.

Osborne, K. (1984). A feminist perspective on women and health. In A. Broome & L. Wallace (Eds.), **Psychology and gynaecological problems** (pp. 266-282). London: Tavistock.

O'Sullivan, J.F. (1982). A mastectomy advisory service. **The Practitioner, 226**, 1422-1425.

Peters-Golden, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. **Social Science and Medicine, 16**, 483-491.

Pfifferling, J.-H. (1980). A cultural prescription for medicocentrism. In L. Eisenberg & A. Kleinman (Eds.), **The relevance of social science for medicine** (pp. 197-222). Dordrecht: D. Reidel.

Polivy, J. (1977). Psychological effects of mastectomy on a woman's feminine self-concept. **Journal of Nervous and Mental Disease, 164**, 77-87.

Ray, C., Lindop, J., & Gibson, S. (1982). The concept of coping. **Psychological Medicine, 12**, 385-395.

Redd, W.H., & Jacobsen, P.B. (1988). Emotions and cancer: New perspectives on an old question. **Cancer, 62**, 1871-1879.

Rimer, I.I. (1976). The impact of mass media on cancer control programs. In J.W. Cullen, B.H. Fox, & R.N. Isom (Eds.), **Cancer: The behavioral dimensions** (pp. 179-186). New York: Raven Press.

Ronis, D.L., & Harel, Y. (1989). Health beliefs and breast examination behaviors: Analyses of linear structural relations. **Psychology and Health**, 3, 259-285.

Rosser, J.E. (1981). The interpretation of women's experience: A critical appraisal of the literature on breast cancer. **Social Science and Medicine, 15E**, 257-265.

Schain, W.S. (1986). Sexual functioning, self-esteem, and cancer care. In J.M. Vaeth (Ed.), **Body image, self-esteem, and sexuality in cancer patients** (2nd ed.) (pp. 15-23). Basel: Karger.

Shukla, H.S., Kumar, S., Avasthi, K., & Naithani, Y.P. (1981). An investigation of delay in treatment of breast cancer. **Indian Journal of Medical Research, 73**, 815-818.

Siero, S., Kok, G., & Pruyn, J. (1984). Effects of public education about breast cancer and breast self-examination. **Social Science and Medicine, 18**, 881-888.

Singer, M. (1989). The coming of age of critical medical anthropology. **Social Science and Medicine, 28**, 1193-1203.

Sontag, S. (1977). **Illness as metaphor**. New York: Farrar, Straus & Giroux.

South African Medical Research Council (MRC) (1987). **Review of South African mortality (1984).** Parow: MRC.

Stein, H.F. (1986). 'Sick people' and 'trolls': A contribution to the understanding of the dynamics of physician explanatory models. **Culture, Medicine and Psychiatry, 10,** 221-229.

Stolbach, L.L., & Brandt, U.C. (1988). Psychosocial factors in the development and progression of breast cancer. In C.L. Cooper (Ed.), **Stress and breast cancer** (pp. 3-24). Chichester: John Wiley.

Swartz, L. (1989). **Aspects of culture in South African psychiatry.** Unpublished doctoral dissertation, University of Cape Town, Cape Town.

Taussig, M.T. (1980). Reification and the consciousness of the patient. **Social Science and Medicine, 14B,** 3-13.

Taylor, K.M. (1988). Physicians and the disclosure of undesirable information. In M. Lock & D. Gordon (Eds.), **Biomedicine examined** (pp. 441-463). Dordrecht: Kluwer.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. **American Psychologist, 38,** 1161-1173.

Taylor, S.E., Lichtman, R.R., & Wood, J.V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. **Journal of Personality and Social Psychology, 46,** 489-502.

Thornton, R. (1988). Culture: A contemporary definition. In E. Boonzaier & J. Sharp (Eds.), **South African keywords: The uses and abuses of political concepts.** Cape Town: David Philip.

Todd, P.B., & Magarey, C.J. (1978). Ego defences and affects in women with breast symptoms: A preliminary measurement paradigm. **British Journal of Medical Psychology, 51,** 177-189.

Trostle, J.A. (1988). Medical compliance as an ideology. **Social Science and Medicine, 27,** 1299-1308.

Twaddle, A.C. (1980). Sickness and the sickness career: Some implications. In L. Eisenberg & A. Kleinman (Eds.), **The relevance of social science for medicine** (pp. 111-133). Dordrecht: D. Reidel.

Vaeth, J.M. (Ed.). (1986). **Body image, self-esteem, and sexuality in cancer patients** (2nd ed.). Basel: Karger.

Vernon, S.W., Tilley, B.C., Neale, A.V., & Steinfeldt, L. (1985). Ethnicity, survival, and delay in seeking treatment for symptoms of breast cancer. **Cancer, 55,** 1563-1571.

Walker, A.R.P. (1989). Cancer balance sheet: Bad news and good news [Editorial]. **South African Medical Journal, 76,** 133-135.

Waters, W.E., & Nichols, S. (1982). Breast cancer: Women's knowledge and attitudes and the difficulties of influencing them. **Community Medicine, 4,** 173-180.

Watson, M. (1983). Psychosocial intervention with cancer patients: A review. **Psychological Medicine, 13,** 839-846.

Watson, M., Greer, S., Blake, S., & Shrapnell, K. (1984). Reaction to a diagnosis of breast cancer: Relationship between denial, delay and rates of psychological morbidity. **Cancer, 53,** 2008-2012.

Wiesenthal, M. (1984). Reach-to-Recovery program of the American Cancer Society. **Cancer, 53,** 825-827.

Yin, R.K. (1984). **Case study research: Design and methods.** Beverly Hills: Sage.

Zemore, R., & Shepel, L.F. (1989). Effects of breast cancer and mastectomy on emotional support and adjustment. **Social Science and Medicine, 28**, 19-27.

Zola, I.K. (1973). Pathways to the doctor: From person to patient. **Social Science and Medicine, 7**, 677-689.

Zola, I.K. (1980). Structural constraints in the doctor-patient relationship: The case of non-compliance. In L. Eisenberg & A. Kleinman (Eds.), **The relevance of social science for medicine** (pp. ,241-252). Dordrecht: D. Reidel.

APPENDIX

Topics for interviews I and II

Experience of past few days - medical procedure and diagnosis

Symptom(s) - evaluation, responses, communication with others

Help-seeking - within social network, health care systems

Illness problems and impact - family, work, social relationships, activities, emotional state, attitude to body

Explanatory models

Health practices and attitude to health and sickness

Medical history

Family background, personal history (education, occupation, relationships, marriage, life events) and current life circumstances

Social supports and coping strategies

Topics for interview III

Experiences of past months

Medical treatment received

Ongoing and changing illness problems and impact

Help-seeking and social supports

Coping strategies

Evaluation of illness and general state of health

Explanatory models

Life circumstances