

**PATIENTS' PERSPECTIVES OF NON-COMPLIANCE WITH MEDICATION AND
TREATMENT REGIMES : A QUALITATIVE ANALYSIS.**

BY

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I certify that it has not been submitted, in part or whole, for a higher degree in any other university and/or institution.

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ABSTRACT.

The importance of compliance as a concept among health care workers is reflected in the amount of research conducted relating to this topic. Various data base programmes such as Medline has revealed 9,718 articles on compliance, which includes 178 on medication and treatment compliance, all written within the last 5 years (1990-1995).

The majority of research in this area has focussed on the subject of non-compliance from the health professionals' veiwpoint, with few studies examining patients' perspectives of non-compliance.

Within the authors' area of work (community nursing), non-compliance with medication and treatment regimes among patients seems to be a recurring problem. Personal experience indicates that little understanding of patients' views on compliance exists among the community health workers, doctors and nurses.

Based on these shortcomings, and lack of reliable literature to satisfy the researchers' curiosity, the author has embarked on this particular research study. The aim of this study is to ascertain the reasons why some patients undermine their physicians' recommendations and do not follow the suggested medication or treatment regimes. The effects of non-compliance by patients has ramifications not only on the health budget, but also on the patient-doctor relationship.

From this study it is hoped that the important issues which patients percieve as influencing their decisions to 'non-comply' will be identified, in order that health professionals can effectively re-evaluate their current practices in prescribing medication and treatment regimes.

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1. INTRODUCTION.

Investigations into the causes of non-compliance have proved inconclusive, even contradictory. The majority of research related to the subject of compliance assumes doctors deliver clear information regarding the drugs they prescribe, and that the patients' failure to comply is purely the fault of the patient. This assumption relates to physician control concepts, and the traditional medical model of health care - where patients remain passive and powerless within the medical encounter (Helman,1990).

Health consumers today are actively seeking more information on their health care options, and are making more informed choices regarding their treatment and medication options, within the context of their lifestyle, needs, beliefs and practices. Within this framework non-compliance should not be seen as deviance - but a result of 'reasoned decision- making' (Donovan & Blake,1992). *"Despite decades of research and thousands of empirical and review publications on the topic, non-adherence is just beginning to be understood as a complex, multivariate phenomenon"* (Dimatteo, Reiter & Gambone, 1994,p.254). Non-compliance is also seen as the product of poor communication and a failure to involve patients in decisions regarding their health and health care needs (Donovan & Blake,1992, Dimatteo, Reiter & Gambone,1994).

a) Definitions of compliance.

To comply is to *"obey, submit, or accede to instructions, or act in accordance with a request or command"* (Oxford English Dictionary, 1990, p.233). Within the health care field, compliance is defined as *"the extent to which a person's behaviour, in terms of taking medications, following diets or executing lifestyle changes, coincides with medical advice"* (Haynes, Taylor & Sackett, 1979, cited in Kelly, 1995, p.40)

Compliance within the context of health, is closely associated with the dominance of medicine, and therefore of obeying doctors' orders (Donovan & Blake, 1992). According to Conrad

" *The whole notion of compliance has a practitioner-centered orientation*" (Conrad, 1985, p.111). It is therefore a concept developed from the practitioners' perspective and is conceived to solve the practitioner defined problem of 'non-compliance'. In this sense it is assumed that the health care worker (primarily the doctor), gives the orders and patients are expected to comply (Place, 1994). "*Compliance, therefore, is a value-laden term that carries with it the idea of submission to another's request or instruction often on the basis of the others' power ; power which may be derived from specialised knowledge and expertise*" (Place, 1994, p.43).

An alternative to the term 'non-compliance', suggested by Donovan and Blake (1992) is 'therapeutic alliance', which aims to remove the concept of power over the patient and replace it with the concept of patient involvement in the decision-making process, when determining medication and treatment regimes.

b) How compliance can be measured.

The measuring of compliance can be divided into quantitative and qualitative methods of research:

Quantitative methods - involve pill counts, biological markers, tracer compounds, and biological examination of body fluids, all of which are considered direct methods of compliance detection.

Qualitative methods - include self-reports and interviews, which are considered less 'scientific' methods of researching compliance and are also subject to interviewer and researcher bias especially during the process of analysis.

2. LITERATURE REVIEW.

According to Dimatteo, Reiter, and Gambone (1994), "*Non-adherence represents a waste of already scarce health care resources*" (Dimatteo et al.1994,p.254). A study by Foreman (1993) shows that the causes of non-compliance include ; drug side-effects, knowledge deficits related to drug dosages and actions, and patient-practitioner relationships - all of which lead to medication non-compliance and higher rates of illness relapse. Another study by Imanaka, Araki and Nobutomo (1993) suggests that patient compliance is influenced not only by rationalisation in decision-making health and behaviour, but it is also influenced by patient satisfaction with health care and communication with health-care providers. Another study by Coons, Sheaham, Hendricks, Robbins, and Johnson (1994) showed that non-compliance with prescribed medications was significantly associated with higher socio-economic status, a greater number of medications, and higher psychological stress.

However, "*Despite decades of research and thousands of empirical and review publications on the topic, non-adherence is just beginning to be understood as a complex, multivariate phenomenon*" (Dimatteo et al.1994,p.254). Non-compliance is seen as the product of poor communication and a failure to involve patients in decisions regarding their health and health care needs (Donovan and Blake,1992, Dimatteo et.al.1994).

a) Quantitative data on non-compliance.

According to Dimatteo, Reiter and Gambone (1994) patient non-compliance with medical treatment is common, with at least 38% of patients failing to follow short-term treatments (i.e. antibiotic therapy), and at least 43% not adhering to long term treatments. Dimatteo et al (1994) also state ; "*The levels of adherence reported vary as a function of the problem, the*

complexity of the regimen, the patient population, and the method of assessing adherence" (Dimatteo et.al. 1994,p.254). The authors further believe the figures given for non-compliance are probably underestimated, and that non-compliance is not confined to a particular group of patients, but tends to occur among people of varying backgrounds, education, and socio-economic levels. Other studies have indicated that non-compliance with prescribed medications is significantly associated with higher socio-economic status, greater number of medications, and higher psychological stress (Coons, Sheaham, Martin, Hendricks, Robbins, and Johnson (1994).

The study by Coons et.al.,(1994), also found no relationship between compliance and health, life satisfaction, number of illnesses, age, or sex.

A study by Donovan and Blake (1992) found that almost half the patients with rheumatoid arthritis were non-compliant with the drugs they had been prescribed. From their study the authors concluded that the majority of patients experimented with the dosages of drugs, and the times they were to be taken. Turner (1987) found that approximately 50% of patients did not follow their doctors' advice and comply with medical treatments. With regard to treatment compliance, a study by Brownell, Marlatt, Lichtenstein and Wilson (1986), showed that more than 75% of patients were unwilling or unable to follow recommended disease prevention lifestyle changes (i.e diet, exercise).

A study by Salzman (1995) suggests that non-compliance with drug therapy in the elderly ranges from 40-75%, with 25% of the elderly taking more than 3 drugs at a time their rates of non-compliance increasing in relation to the amount of drugs prescribed. This is an important consideration when treating elderly patients as a study in Sydney showed that 27% of the elderly who live in their own homes, and nearly 50% of those living in nursing homes were taking more than 4 medications regularly (Snowdon,1993).

b) Reasons for non-compliance.

There are a number of reasons, or causes, of non-compliance with medication regimes which have been identified in research studies over the past 10 years, the results of which some authors have divided into influencing themes and factors. For example, Helman (1990) divides the influences on non-compliance into internal and external factors. Internal factors include ; prior experience; patients' expectations; cultural assumptions; social status; gender and religion - all of which Helman argues affects patient and practitioner interaction and ultimately patient compliance. External factors include the patient/practitioner setting (i.e hospital, clinic, patients' home), and the wider social influences of ideology and economics - all which defines who holds the power within the consultation episode (Helman,1990).

Geest, Abraham, Gemoets & Evers (1994) studied patients perceptions, experiences and practices associated with long term medication therapy, and divided areas of non-compliance into ;psychological, environmental, and behavioural factors. For the purpose of this review each of these factors will be used as headings to review the findings of the Geest et.al (1994) study and associated research studies. Below the influence of these latter factors in relation to compliance are discussed in detail.

PS YCHOLOGICAL FACTORS AFFECTING COMPLIANCE.

Stress.

Emotional distress was identified in 2 studies as a factor affecting compliance - whereby the higher a persons perceived stress the more likely they were to non-comply (Geest et. al.1994; Coons, Sheahan, Martin, Hendricks, Robbins and Johnson,1994).

Patient and practitioner relations.

In many of the studies patient and practitioner relationships had an important influence on a patients' ability, or desire, to comply with medications or treatment regimes (Geest et.al.,1994; Chen,1991; Imanaka, Araki and Nobutomo,1993). Reasons for non-compliance included; conflicting advice from health professionals; practitioners' attitudes towards patients; poor communication; and failure to involve patients' in decision-making processes (Zola,1981; Imanaka et.al.,1993; Donovan & Blake,1992).

Perceived health status.

In a study by Salzman (1995), patients who considered themselves acutely ill tended to take more than the prescribed dosages of medications - in the belief that they would get better quicker. In another study by Imanka et.al.,(1993), patients who considered their illness to be minor took less than the prescribed dosages of medications. Both the overuse, and underuse, of medications are considered forms of non-compliance, and can lead to adverse drug side-effects in some patients.

Memory loss.

Forgetting to take medications is a particular problem for the elderly, especially if a number of drugs need to be taken. Salzman (1993) estimates that 25% of the elderly population take 3 or more tablets per day, and that a typical hospitalised patient takes an average of 8 drugs at a time. Salzman (1993) concludes from previous data on this topic that the use of more than 3 tablets per day increases an elderly persons' risk of non-compliance.

Satisfaction with care.

This factor was identified in a study by Imanaka et.al.,(1993), who found that patients' satisfaction with their medical care influenced their compliance, i.e. satisfied patients were more compliant.

Beliefs and practices.

Patients who believed in the efficacy of prescribed medications had increased compliance levels. In a study by Kelly, Mamon & Scott (1987) the relationship between health beliefs and medication compliance among psychiatric patients was studied. Data from this study showed that patients hold; " *Distinct and realistic beliefs and perceptions regarding the extent of their illnesses and the ways they are viewed by others around them*" (Kelly et.al.,1987,p.1209). The authors of this study concluded that compliance was improved if health providers considered patients' lifestyles, and health beliefs and practices when planning medication and treatment regimes.

ENVIRONMENTAL FACTORS.

These were divided by Geest et.al (1994) into themes of; routine, distraction, social support, and cost of medications - all of which affect a patients' ability to comply.

BEHAVIOURAL FACTORS.

There is a limited amount of research relating to how patients' feel and think about their illnesses and treatments - and how this affects their decision to non-comply (Donovan & Blake,1992). A few of these studies, as reported below, reflect some of the reasons which contribute to a patients' status of 'non-compliant'.

Side effects of medications.

Side effects are a significant factor in a patients' decision to begin, or continue, a drug regime (Geest et.al.1994; Foreman,1993; Donovan & Blake 1992). Obviously drugs with unpleasant side-effects are more likely to be discontinued by patients, but this also links to the patients'

perceptions regarding the severity of their condition (i.e patient's with cancer having chemotherapy may be fully compliant despite the distressing side-effects these drugs produce).

Drug delivery system.

The system available to patients' in the delivery and dispensing of medications was identified by Geest et.al.(1994) as important in determining patient compliance. An important aid for patients' with memory deficits is the use of a dosette box (see appendix A) which can significantly improve compliance.

Medication schedules

Many patients experiment with drug dosages and times appropriate to their lifestyles, habits and routines, resulting in either underuse or overuse of medications (Donovan & Blake,1992; Salzman 1995, Geest et.al. 1994). Patients often self-assess a drugs effectiveness and alter doses accordingly (Salzman,1995, Coons et.al.1994). Salzman (1995) states that the most common non-compliant behaviour in the elderly is the underuse rather than the overuse of prescribed medications. Salzman (1995) also found that the discontinuation of drug therapies occurred in up to 40% of prescribing situations - particularly within the first year of a drug regime. Self medication practices are also relatively common with 10% of the elderly taking drugs prescribed for others, and more than 20% taking medications not prescribed by a physician.

Knowledge.

A number of studies showed that the amount of information patients' received on their illnesses and drugs prescribed had a positive effect on compliance - i.e the more information they received the higher the rate of compliance (Geest et.al. 1994; Dimatteo et.al. 1994; Foreman, 1993). This finding is further substantiated in a study by Youssef (1983) who investigated the impact of patient education on compliance following discharge from hospital. The participants

were randomly divided into two groups, one group receiving education, and the control group, who received no education. The results showed that the group who received education had a statistically increased compliance with medications compared to the control group.

Control.

Conrad (1985) identified patients' as needing to feel in control of their illnesses and this control involved patients' deciding themselves which medications and treatments may, or may not, benefit their health status.

Fear of dependency.

In a number of studies patients' felt that being dependent on drugs removed their own feeling of control over their illness, and that this dependency was detrimental to their recovery (Donovan & Blake 1992). This is a particular problem for the chronically ill patient who needs to accept their dependency on drugs - which control the disease process and enable them to attain a reasonable quality of life.

To summarise, there are a number of important factors to consider when investigating reasons for non-compliance. Many of these factors are based on the ability of the health practitioner not only to understand and appreciate patients' lifestyles, health beliefs, and practices, but also to consult and educate patients when planning medication and treatment regimes.

2c PATIENT INTERACTION WITH HEALTH PROFESSIONALS AND ITS AFFECT ON COMPLIANCE.

i)The Biomedical Model.

The health provider and consumer relationship has become a central concern in the study of the biomedical model of health, especially as the relationship between the two provides the key to good medical practice (Finkler, 1994).

As a result, in order to provide services which are relevant and acceptable to all, an understanding of the relationship between service provider and consumer becomes necessary.

Historically, health practices have been primarily based on a western biomedical approach, which differs considerably from the health beliefs and practices in many non-western cultures (Leninger, 1970).

Some authors consider the biomedical model focuses on the negative aspects of a patient's condition, and directs efforts towards treating illnesses, thus failing to consider the wider 'holistic' view of disease causation (Armentrout, 1993 ; Engel, 1977; Kleinman, 1980). The failure of the biomedical model to include psychosocial, environmental, and cultural factors in disease causation according to Armentrout (1993) has impeded further advances in health care. According to Finkler (1994) biomedicine treats..."*individual bodies, without transforming peoples' lives*", and thus it .."*fails to contribute to new social forms for the collectivity. It succeeds only in maintaining its hegemony as the major authorized provider of health care legitimated by the state*" (Finkler, 1994, p.192).

This inability to be sensitive and responsive towards differing social and cultural needs has resulted in unsuccessful, and culturally inappropriate health programmes and resultant non-compliance, especially in Aboriginal communities and Non-English speaking background groups here in Australia - all of whom receive limited services and suffer poorer health

(Eckerman & Dowd, 1992; Freeman, 1994; Spector, 1979). By examining the health provider and patient from a cultural perspective, an appreciation and understanding of these two separate viewpoints, can lead to more culturally appropriate programmes and treatments which benefit both provider and consumer and in turn lead to increased levels of compliance.

Generally, health care providers adhere to the biomedical model of health, and tend to dismiss alternative treatments or practices unless they are scientifically proven to be effective (Zola, 1979). This may lead to misunderstandings and conflict between health providers and consumers (patients). According to Zola (1979), the health service provider's culture within the biomedical model covers the following three issues ;

1. Health and illness have standard definitions, and technology is considered omnipotent.
2. Health practice is aimed at maintenance of health, and disease prevention, which is achieved by immunizations, screening, and diagnostic procedures.
3. The practices and habits of health care providers include charting, and the use of specialized language - which excludes the patient from understanding. They also practice a systematic approach to problem solving, and exhibit specific behavioural patterns which include promptness, neatness, organisation, and patient compliance - all of which are considered ideal.

Each of these issues have differing consequences for health care providers and their clients.

Standardized definitions and use of technology, suggests technology is omnipotent by placing more emphasis and reliability on technical measurements than the patients' own accounts. This results in treatments being based on the premise that the patients' behaviour needs to be modified (Engel, 1977). Furthermore, the assumption that scientific knowledge is superior to commonsense understanding of life events undermines the ability of individuals to understand their own bodies (Hewa & Hetherington, 1993).

The introduction of diagnostic and screening procedures, which maintains physician control is maintained by encouraging 'check-ups', so that individuals gain confidence in their physicians, who retain control of their patients' health status (Armentrout,1993: Hewa & Hetherington,1993: Illich,1975). Screening is also described by Armentrout (1993) as producing fear in patients - which is further used as a motivator for patients to seek health checks, and results in patients' loss of control, and dependency on their physicians. Illich (1975) illustrates this point by stating that a persons' natural ability to cope with life events is replaced by a dependency on expertise, and he describes screening programmes as an; "*extension of professional control over the care of healthy people*" (Illich, 1975,p.48). By depending on physicians during sickness and health episodes the consumer turns into a "life-long patient" (Illich, 1975, p. 50). Finally, the practices, beliefs, and habits of health care providers, also influences the relationship they may have with their clients. In this context, health care providers may lack an appreciation for their clients' cultural background, beliefs, and health practices (Kleinman, 1980), all of which can affect the patients' illness, recovery, behaviour, and attitude, (Leininger, 1970). This often leads to patient non-compliance regarding their treatment, and is common in communities where health practitioners assume a dominant, culturally insensitive role (Eckerman & Dowd, 1992).

Further domination of patients by health providers occurs through the use of medical jargon. This is clearly illustrated in Eckerman & Dowds' study of Aboriginal communities - where an Aboriginal woman complains of a lack of understanding when talking to doctors and nurses. She states they "*use long words and talk too fast - bad for understanding, so we just sit there dumb*" (Eckerman & Dowd, 1991, p.18). Zola (1981) also discusses medical language which; "*..both in tone and content often patronizes and thus further intimidates, and even confuses the patient*" (Zola,1981,p.246). This alienates the patient, and places them in a subordinate role

which is described by Kleinman (1980), as "*fostering and maintaining a childlike dependence and depersonalisation*" (Kleinman,1980, p.57). The doctor is thus projected as a superior human being with more knowledge, power, and control over their clients' health . Patients within the biomedical model of health care are thus seen as victims, passive and powerless to prevent disease occurring within themselves (Armentrout, 1993).

Another form of control within the biomedical framework instills fear into patients by using such threats as ; 'if you don't take your tablets you'll get sick'. This approach is used by health professionals to maintain a patients' compliance, and relinquish responsibility. Such an approach also treats the patient as a passive recipient of health care, with little or no control over their health status (Armentrout, 1993).

In summary, the interaction between health provider and consumer, within the biomedical framework, is based on the production of fear, loss of control, alienation, and dependency. A more holistic approach, where practitioner and patient share authority and equal status within the health interaction, results in partnership and collaboration - which, from the studies conducted in this area, results in higher levels of compliance (Lowenberg, 1994).

ii) The holistic health model.

Different studies have shown that compliance is improved by encouraging practitioners to become more 'patient-centered' and empathetic (Henbest & Steward,1990; Squier,1990). This is achieved by encouraging patients to ask more questions (Rost, Carter & Inui,1989), and by fostering greater co-operation between practitioner and patient (Donovan & Blake, 1992). Lowenberg (1994), suggests that 'holistic' health interactions result in a partnership in decision making - which is achieved by both practitioner and patient taking active roles in the

interaction, and the practitioner taking the role of adviser, rather than decider of treatment and medication options.

Discourse in medical and nursing literature includes the frequent use of terminology such as "compliance" - which indicates a continuing power differential (Lowenberg,1994). With this in mind, and the preferable use of a more holistic, collaborative approach to health care, the term 'compliance' should be replaced. A suggested new term is "active alliance" - which implies a more active role for patients, and shared authority and equal status within the health professional/patient interaction episode (Zola, 1981).

iii) Patient Behaviour.

In his article titled 'structural constraints in the doctor-patient relationship : The case of non-compliance', Zola (1981) discusses the reasons for non-compliance and states; "*Nearly 50% of patients stop taking their medications long before they are supposed to. Many take the wrong dose at the wrong time. And many more than we realise don't even fill their prescriptions*" (Zola,1981,p.241). The reasons for this Zola states, are due to the fact that ; "*We do not sufficiently appreciate what following a medical regimen means to an individual, nor do we fully acknowledge the role that the health personnel have in contributing to the very non-compliance we seek to reverse*", (Zola,1981,p.241).

While some people go to the doctor at the first sign of trouble, many delay the visit and go reluctantly. Zola (1981) cites a number of studies which show that most people are fearful of going to the doctor, and that a complex set of social events forces them to go (Anderson, 1968; Freidson,1961; Suchman,1965; Zola,1975). Often a patients' condition is chronic by the time

they seek a medical opinion, which means that the patient has learnt to cope with the illness and may have tried alternative therapies before seeing their doctor (Zola, 1981).

Zola (1981) also describes disease as a 'social phenomenon', which involves not only the patients' family, but also aspects of their lifestyle (i.e occupation). Therefore, if a doctor suggests a change in occupation or lifestyle to a patient- this advice may seem not only ridiculous in the patients' view but also impossible to attain - which inevitably leads to non-compliance.

iv) Lifestyle issues.

Zola (1981) considers that many patients ; "*regard much of their treatment as unwanted, intrusive, disruptive, and the manner in which it is given presumptuous*" (Zola, 1981,p.242).

Zola (1981) argues that the prescribed medication or treatment needs to be compatible with the patients' own lifestyle. The issue of trust between patient and doctor is established during the initial consultation, where the doctor explains the treatment carefully and in detail - so that the patient is fully informed and aware of potential side-effects which may be experienced. If medications and their mode of action are not fully explained, many patients will discontinue treatments and begin to distrust their doctor- leading to a history of non-compliance with medications or treatment.

A number of studies also suggest that patient non-compliance is a result of the patients' "uncooperative personality" (Zola,1981,p.243). Often the patient is blamed for not understanding the physicians' instructions. Zola also refers to other studies which indicate that many doctors underestimate their patients' non-compliance, and are unable to identify which of their patients are more likely to be non-compliant (Balint, Hunt, Joyce, Marinker & Woodcock, 1970; Barsky & Gillum, 1974; Davies, 1966).

v) Information.

Patients are expected to remember too much information, during their consultation with the doctor, in a limited amount of time (Zola, 1981). Often medication or treatment instructions are not specific, and are open to the patient's own interpretations - which in turn leads to incorrect medication usage, i.e. 'take this tablet 4 times a day'- may cause a patient to wake up at night to take the medication. Or 'keep your leg elevated most of the day' does not indicate how high to elevate the leg, or whether it also needs to be elevated when lying down, (Zola,1981). From these examples it is obvious instructions need to be explicit when explaining medication and treatment regimes, and that the more information that is given by the health professional, the greater the likelihood of patient compliance (Davies,1968; Zola,1981).

Zola (1981) suggests the answer to improvement lies in more open communication between doctors and their patients. To help achieve this Zola (1981) suggests an environment where the information giving process is divided, i.e separate from the diagnosis session, a further session is arranged where patients may be more receptive to the information they are given, and are no longer in a state of shock. Also the presence of a relative or carer can assist in the accurate recall of information.

Finally, a solution to all these communication barriers will assist the patient and health professional decide the relevant and appropriate care and treatment. To achieve this Zola (1981) states ; "*There must be less talk of persuasion and more of negotiation. And when we do so, a change in philosophy will be reflected in a change of language. We will no longer speak of medication compliance but rather of 'therapeutic alliance'*", (Zola,1981,p.250).

2d) SOCIAL THEORIES AND COMPLIANCE.

When social sciences began to investigate compliance from the patients' perspective, issues of attitudes, communications, behaviour, and the health care structure were all seen to affect this issue, (Barnard,1988).

Barnard (1988) explains that the human exists and functions within a social context in relation to their interactions with others. Thus the stimulus to seek medical aid arises ; *"From the loss of the ability to perform customary social roles., from anxiety due to anticipated threats to ones' social existence, or from the desire to experience in the health care system a form of social contact that is felt to be unavailable in ordinary living"*, (McWhinney, 1972).

Barnard (1988) argues that the health care system is organised around an increasingly medicalised technology, and has resulted in health professionals themselves becoming specialised in areas of medical care. *" As social events, the ministrations of health professionals help define the sick persons' status within the community. From the patients' perspective, they can either reinforce or diminish his or her sense of connection"* (Barnard, 1988,p.93). Barnard also states that illness heightens peoples' need for attachment, and this type of behaviour is connected to peoples' experience of illnesses and healthcare. There is also epidemiological evidence which suggests that people who have lost a significant attachment figure are; frequent users of health services ; have a higher risk of physical disease ; recover more slowly from disabilities ; have a higher risk of non-compliance; and require more support from health professionals, than people whose social network is intact. As Barnard suggests ; *" Going to the doctor is itself an example of attachment behaviour "* (Barnard,1988,p.104).

i)The Health care System.

The health care system encompasses a variety of sub-cultures, which incorporate varying beliefs, and patterns of behaviour - all governed by the individuals own set cultural rules or norms (Kleinman, 1980). These beliefs and behaviours are also influenced by the institutions in which they are contained i.e clinics, hospitals. They are also influenced by social roles ; i.e. the sick role, healing role, and interpersonal relationships between the doctor and patient, interaction settings i.e. home or surgery, and economic and political constraints together with the factors of treatment availability, and type of health problem to be treated (Kleinman, 1980). Health care therefore needs to be considered as a system which is "*Social and cultural in origin, structure, function and significance*" (Kleinman,1980,p.27).

Individuals' cultural beliefs and attitudes towards sickness and healing differ, as do their choice and evaluation of health care practices (Kleinman,1980). Consequently, the health care system, although created by a collective view and shared pattern of usage, is seen differently by social groups, families, and individuals. As a result, a health facility may contain a diversity of beliefs, systems, clinical roles and healing practices.

The popular sector of the health system is described by Kleinman (1980) as the largest part of the system, and includes individuals, family, social networks, community beliefs and activities. It is the 'lay', non-professional areas in which illness is first defined, and health-care initiated. According to Kleinman (1980) in American society 70-90% of all illness episodes are managed within this sector. This sector interacts with other sectors - i.e. folk and professional sectors, but it remains the initial step whereby individuals decide when and whom to consult.

One of the individuals' first steps towards healthy living may be self-medication, having labelled and validated their illness, they will decide to either treat it themselves, or seek professional

advice. They may use treatments which are familiar, or may consult with family and friends for advice (Kleinman,1980). Following this the individual may enter one of the other sectors. Once this happens the individual may encounter differing beliefs and values among the professional and folk practitioners. Also within each of the sectors, the individual experiences differing roles and expectations. For example in the popular sector the individual may be a sick family member, in the professional sector a patient, and in the folk sector a client (Kleinman,1980). Each sector in turn contains its' own entrance and exit rules. Within the popular sector the individual assumes a sick role within a family or social setting. In the professional sector, the sick person enters by becoming a hospital patient and exits cured, still sick, or terminal.

ii)The sick role.

Parsons (1951) classified sickness as a form of deviant behaviour requiring legitimization and social control. While the sick role legitimizes social deviance, it also requires an acceptance of medical regimes. The sick role was therefore an important vehicle for social control, with the aim of the medical treatment being to return the sick person to conventional social roles (Parsons, 1951). The aim of treatment was to remove the patient from the sick role and return them to the social environment - all of which involves activism and obligation on the part of the patient.

Conversely, Turner (1987) suggests that the sick role may cause an individual to avoid responsibility for their sickness, and retreat from the demands of society. In this sense the doctor provides the gateway for legitimized withdrawal from social roles and their attached responsibilities. This can lead to conflicts of interest, where the doctor is committed to

healing the patient, but the patient is committed to staying sick - which in turn leads to patient non-compliance.

Medication regimes are also considered a cursory answer to solving patients' social problems;

" Pills are promoted as magic fixes to social discontent, as they end a consultation and allow the doctor to feel useful in coping with someone's distress in a short period of time"

(Chapman,1979, Cooperstock & Lennard, 1979 - cited in Davies & George,1993,p.196).

From this discussion it can be concluded that the affect of the sick role and its' associated position within society can also affect a patients' attitude towards compliance with treatment and medication regimes.

3e) BIOMEDICINE AND IATROGENESIS.

The historical development of the Biomedical model.

The biomedical model of healthcare has dominated the concept of disease in the western world since the middle of the 19th century - when it became the basis of medical practice and academic medicine (Ahmed & White-Fraser,1979).

The model is based on the germ theory of disease, which regards illness as the result of viruses, bacteria, and malnutrition. This discovery transformed medicine from a *"People orientated, to a disease orientated profession"* (Twaddle & Hessler, cited in Ahmed et.al.,1979,p.115)

It was devised by medical scientists, for the study of disease, and is based on the premise that any deviation from normal health in an individual represents disease and that the cure will automatically result in health improvement (Engel,1977). It has been described by Kleinman (1980) as ethnocentric and reductionist, and as having no spiritual component - thus separating

mind from body (Armentrout,1993; Shaver,1985). Its' approach is problem orientated, dealing primarily with illness by which a diagnosis is made and treatment suggested, and limited health maintenance advice is given to the patient. Biomedicine is also committed to preserving life to the extent of using extreme measures, with little regard for quality of life (Armentrout,1993). The model views patients in terms of their diagnosis - which leads to labelling and a focusing on parts of the patients' body which require treatment- and by which the patient comes to be identified (i.e 'the appendicectomy in bed no.4).

The failure of the biomedical model to include psychological, environmental, and cultural factors in disease causation and treatment, has impeded further advances in healthcare (Armentrout,1993) and has caused patient disillusionment with traditional medicine - resulting in increased levels of non-compliance.

From this, a change in trend has occurred among consumers who are disenchanted with increasing medical technology and the narrow focus of the medical model approach to health care. Alternative practitioners such as Herbalist's, Homeopaths, Chiropractors, etc, are becoming increasingly popular, thus giving consumers greater choice and control in treatment options and involvement in their health decisions - which in turn leads to an increased likelihood of compliance with treatment and medication regimes.

The growth of medical technology within the biomedical model .

Medical technology is defined as ; "*The set of techniques, drugs, equipment, and procedures used by health care professionals in delivering medical care to individuals and the systems within which such care is delivered*" (Banta & Bahney,1981,p.447).

The authors Hewa & Hetherington (1993), in their paper 'The rationalization of illness and the illness of rationalization', argue that medical technology has continued to gain control of human

life by eliminating peoples' ability to function independently. Also, by making illness and treatment processes more technical, the publics' understanding of these processes is greatly reduced (Hewa & Hetherington,1993).

Further discussion on the affects of medical technology on society is given by Illich in his book 'Medical Nemesis'. Here Illich (1975) states that .."*Medical technology has combined with egalitarian rhetoric to create the dangerous delusion that contemporary medicine is highly effective*" (Illich,1975,p.19). Illich continues by arguing that instead of medical treatment being effective against treating disease, it can produce dangerous side-effects, a condition which he calls 'iatrogenesis' (from the Greek 'Iatros' meaning physician, and 'Genesis'- relating to origin).

This new form of illness is also described by Armentrout (1993) as medically induced through the increased use of inappropriate drugs and surgical procedures. This point is further substantiated by Beaty & Petersdorf (1966), who state; "*The most important principle in the prophylaxis of iatrogenic disease .. is to administer drugs only when they are needed and to perform diagnostic procedures only when they are likely to yield meaningful information*" (Petersdorf,1966).

As a result of increases in medical technology it is argued that the health status of many people has declined and costs of health care have increased (Hewa & Hetherington,1993 ; Feeny, 1986; Shaver,1985). The cost of purchasing medical equipment for open heart surgery, brain scans, and other diagnostic tests is unjustified - according to Hewa & Hetherington (1993), as the equipment is both under-utilised and duplicated.

This growth in medical technology has further lead to the conclusion that what is "*Technically possible, rather than what is medically essential determines what is done*" (Hewa & Hetherington,1993,p.147).

In order to control the over-medicalization of health the authors Ahmed et.al (1979) suggest that health professionals need to re-focus their training to incorporate social, psychological and cultural factors into both their diagnosis and treatment of patients. From this discussion it seems alternative strategies are required to prevent the domination of medical technology and improve public understanding of illness and health and empower them to control their own bodies and health status.

From this the biomedical backlash has developed - taking the form of public debates and legal campaigns where medical interventions are argued and discussed (Hewa & Hetherington, 1993). Much of the debate hinges on the premise that medical treatments do not always improve the patients quality of life. As a result of these debates the public are becoming more aware of their need to accept responsibility for their health rather than relying on medical personnel to cure their illnesses.

Iatrogenesis and medications.

In their book "States of Health" (1993), the authors Davies and George indicate that a large number of the population have been identified as regularly using prescription and other medicines. Multiple prescribing can also lead to drug interactions and adverse side -effects, which account for 10-15% of hospital admissions, (Hicks 1981, cited in Davies & George, 1993). The problem of these side-effects and drug reactions lies in our readiness to take medications for various illnesses and the fact that these medications are now so powerful and readily available - that damaging side-effects more commonly occur (Davies & George 1993). According to Mant (1979) the use of drugs is higher in the working class, and among the elderly, widowed, divorced, separated, and women. The world consumption of drugs in 1980 was valued at \$80 billion (Davies & George, 1993). This growth in the consumption of drugs

can be linked to marketing by the drug companies towards the medical profession. According to Davies and George (1993) 20% of the cost of developing new drugs is spent on advertising, marketing, and selling. For example, Illich (1976) states that \$200 million was spent by Hoffman La Roche over a period of 10 years to promote valium. Together with the growth in medical technology and the strength and variety of modern drugs, the consumer is faced with a multiplicity of technical and medical interventions - this has led to patients' questioning the efficacy and value of these interventions in relation to their health and lifestyle choices.

From this discussion it seems that alternative strategies are required to prevent the domination of medical technology, and improve public understanding of illness and health, and enable people to control their own bodies and health status through a variety of treatment options which are compatible to their beliefs and lifestyles, which in turn would hopefully result in greater levels of compliance in treatment and medication regimes.

2f) THE AFFECTS OF NON-COMPLIANCE.

According to Dimatteo et al, (1994), non-adherence represents a waste of already scarce health resources. In addition, because health care workers are often unaware of a patients' non-compliance with medications or suggested treatment regimes, the patients' diagnosis may be confused. This may lead to inappropriate tests and procedures and possibly harmful changes in medications and their dosages.

Walton, Duncan, Fletcher, Freeling, Hawkins, Kessel and McCall (1980) suggest that wasted drugs as a result of non-compliance may well cost in excess of \$600 million per year in the UK

Consequently, the cost of non-compliance can not only be seen in wasted funds and resources, but also as detrimental to a patients' ultimate health status and recovery from illness.

2g) HOW COMPLIANCE CAN BE IMPROVED.

In an article by Frank, Kupfer and Siegal (1995) titled ; 'Alliance, not compliance : A philosophy of outpatient care' effective methods to improve treatment alliance with mood disorder patients was researched. Their results showed a low patient drop-out rate (less than 10%), and a high rate of medication compliance (over 85%). The authors considered their methods for improving compliance (or alliance) could be applied to patients in general clinical practice (their study dealt with psychiatric patients).

The basis of their methods were ;

1. Education.
2. Information.
3. Active participation.

The first step was to educate the patient about their disorder and its' treatment and involved giving them as much information as possible (with regard to their mental capacity for retaining information). As the patients' condition improved, they were given additional information. Further explanations regarding what the patients should expect during their treatment and side-effects they may experience was also given. The authors considered the physicians experts on the disorder and relevant treatment, and the patients' were considered experts on their own disorder and their individual experiences of the treatments.

Bond and Hussar (1991) investigated the reliability of compliance detection methods and strategies aimed at improving compliance with drug therapies. The authors found that the successful strategies for improving compliance involved ;

1. The identification of risk factors for non-compliance.
2. The development, with patient participation, of an individualised treatment plan - which is as simplified as possible.
3. Education of the patient - including information about their illness ; how to take the medications correctly ; explanations of the benefits and adverse side-effects of the drugs, and the use of compliance aids i.e. calendars and dosette boxes , and also patients should be taught how to monitor their own treatment regimes. The authors of this research concluded that ; *"Health care practitioners need to understand factors that contribute to non-compliance and to use affective methods for assessing and monitoring compliance in conjunction with strategies aimed at increasing compliant behaviour"* (Bond & Hussar, 1991,p 1978).

Similar conclusions were made by Foreman (1993) who suggested compliance could be improved by a combination of the following concepts ;

1. Continuing assessment and understanding by the health professionals of the patients' reasons for treatment resistance.
2. Patient education - which promotes medication adherence.
3. Not viewing the patient as the guilty party - but sharing the responsibility of compliance between health professional and patient.

Within the same paradigm, Dimatteo et al., (1994) suggest a system called P.R.E.P.A.R.E.D. which they state enhances informed collaborative choice in adherence to medication treatment. This system is designed to enhance patient-provider communication and patient self-efficacy and satisfaction by combining their expertise on treatment choices.

According to Kleinman (1980) theories to improve compliance are based on 5 topics discussed between health practitioner and patient which are ;

1. Cause of illness.
2. Onset of symptoms.
3. Pathophysiology.
4. Course of the illness - including beliefs about the type of sick role and the severity of the illness.
5. Treatment goals.

A further influencing factor in this issue is the doctor-patient relationship, which is crucial to patient conceptualizations in the significance of the sickness. This sharing of information between doctor and patient has been shown in various studies to improve compliance, and it is also important as a basis for achieving a patients' co-operation with the treatment process (Turner,1987). Successful communication with the patient is an important aspect of the therapeutic process - as successful interactions may restore the confidence and sense of well-being for the patient (Turner,1987).

Finally, for medical treatment to be acceptable to patients it must make sense in terms of their own beliefs about sickness, illness and disease.

In conclusion, a number of important issues arise in the area of compliance and in relation to the health system and its treatment of patients. The three main areas discussed to improve compliance indicate that ;

1. Improved information and explanation on drugs and treatment regimes improve compliance.
2. Patients' health beliefs, and attitudes have a significant influence on a persons' initial desire to seek treatment and adhere to prescribed regimes.

3. Finally, the interaction between health professional and patient relates to the setting in which it occurs and the processes of communication, power and control - all of which affects a patients' ability to decide and control their own health status - a position which most patients ascribe to but a situation which so often does not occur in the doctor-patient interaction scenario.

RESEARCH STUDY.

This research study examines the perceptions patients, as consumers, have of health and illness - and how these beliefs and attitudes affect their compliance with medication and treatment regimes.

By choosing qualitative research methods, this study is an attempt to examine the conceptual aspects of patients' behaviour, in order to gain a better understanding of the range and depth of patients thoughts and feelings concerning their health.

In order to understand health from the patients' perspective, the use of qualitative research is integral in understanding patients' behaviour at a conceptual level.

"Qualitative researchers seek to uncover the thoughts, perceptions and feelings experienced by informants. They are most interested in studying how people attach meaning to and organise their lives, and how this in turn influences their actions" (Minichiello, Aroni, Timewell, Alexander, 1990, p.6).

In determining the methodology for this research project, it was decided to use in-depth interviewing, as an appropriate qualitative research method. The interviews were conducted in the informants' homes, at the hospital, and in a day centre, and were taped and transcribed for analysis. Analysis of the interviews centred around the identification of themes and conceptual categories of health and illness as identified by the informants.

1) The results of this study will enable the researcher to develop community nursing assessment criteria which consider the findings of this research and apply them to current practices. It is envisaged that this assessment will consider patients' health beliefs in relation to treatment options and lead to improved decision-making options, and consequently improved patient 'compliance' with appropriate and relevant treatments.

3) METHODOLOGY.

When considering the appropriate research design, it was decided to base this study on ethnographic - inductive research methods, in order to gain an understanding of the perceptions and experiences of patients within the health system. *"In ethnographic-inductive designs, researchers often take the view that the theory, the explanations, the connection between action and interpretation, should be suggested by the social system itself. They are interested in immersing themselves in the social system, or accounts of that system, and developing the theory by observing how patterns of meaning emerge from the social practices and beliefs of those they are studying"* (Kellehear, 1993, p.21). The aim of the study was to gain a view of the patients' interpretations of their health and their relationship with the health professionals they come into contact with - two concepts which can be described as *Phenomenology*, and *Symbolic interaction* (Kellehear, 1993, p.27). Phenomenology describes experience as being social and shared, and is based on the premise that our experience of the world depends on our ability to detach ourselves from our usual notions and examine the 'stream of consciousness' - of our past, present, and anticipated experiences, (Wild, 1985). Symbolic interaction assumes that social life develops from within society out of the process of interaction between individuals. In this context society is seen as undefined and unintegrated, (Wild, 1985). By examining the concept of symbolic interaction, the relationship between health professional and patient, and the environment (the health system) in which this interaction occurs can be examined. Within this research, the aim was to look at the health system as a cultural system by taking an ethnomethodological approach and attempt to determine how meanings concerning health are derived and established through interaction and participation.

3a) Ethical considerations.

To gain access to the informants, ethical approval was sought from both the Community Health Ethics Committee at the university, and also a nursing organisations' ethics committee. An explanatory letter was compiled, introducing the research as a study of medication and treatment regimes (see appendix B). Also a consent form for the participants to sign was given to all informants, which outlined their right to withdraw from the study at any time, and that the tape recording of the interview would be destroyed following its' transcription. The consent form also stated that the participants' identity would also be protected . Another important issue was to ensure that the informants did not feel their nursing or medical care would be influenced by their participation, or non-participation, in the study - this was also clearly outlined in the explanatory letter.

Following the interview the informants were given the researcher's contact number in case they felt the need to discuss the interview further, or any other aspects of the research study.

3b) Sampling.

The purpose of sampling is ; *"to produce either a sample which is representative of a chosen population or which may illuminate a situation, get insight, or collect information about a particular event"* (Wadsworth, 1984, cited in Minichiello et.al.,1990, p.197).

Within this research the issue of sampling was important in order to obtain a range of views and ideas. The aim was to interview 5-10 respondents, and the identification of the sample would focus on patients who were non-compliant with treatment or medication regimes. Treatment in this context included special diets (i.e low fat), types of wound dressings, investigative procedures (i.e x-rays, scans, screening procedures etc).

The sample was obtained from a variety of settings ; community nursing services, General Practitioners, and hospital outpatients. Snowballing techniques were used to identify potential respondents, whereby staff at each location were informed of the research proposal and asked to identify potential respondents who could be approached directly. From this list a random selection from each location was made.

The initial size of the sample group was small due to the time restrictions. The interviews were conducted in the informants' homes, at the hospital, and in the day centres.

3c) Interviews.

In-depth interviewing techniques were used, to gain information regarding the informants' (or patients') perceptions of their self, and life experiences in relation to their health - which they were able to communicate in their own words. By expressing their beliefs in their own words, the use of medical jargon was avoided. By using the in-depth interviewing method it was hoped the informants would be able to describe their illnesses, treatments, and beliefs in a way which proved relevant to them - rather than in a medical model format. This perspective is described by Minichiello et al (1990) as a 'Symbolic interactionist' approach, whereby the patients' perspective is sought by the use of their own words and interpretations.

Unstructured interviewing methods were used, as opposed to focused, or structured methods, so that the informants could express their views freely. There was some guidance in the course of the interview, by the interviewer - so that the topic of the research subject was covered. But this guidance was limited, to allow greater flexibility. In this sense, there was no order of questions, and the interview took the form of everyday conversation.

By working within the medical model framework the researcher was aware of the use of medical jargon, and of describing health and illness within a medical model context. Furthermore, the interviewers' position as a health professional could result in the researcher controlling the interview process and outcome, and this was hoped to be avoided by the researcher being aware of this possibility and by developing a more egalitarian approach during the interview process.

From the interview data, a 'grounded theory' approach was developed - whereby theory was compiled from the data gathered (Minichiello et.al. 1990).

The interview itself initially established effective rapport, as the aim was to understand the informants' perspective by becoming sensitive in both the questioning techniques, and use of appropriate language. The recursive model of interviewing was used, which is described by Minichiello, et.al.,(1990) as ; "*The interaction in each interview directs the research process*" (Minichiello, 1990, p.112).

The questioning took the form of a discussion, whereby the natural flow of the conversation was encouraged. To re-focus the informant on the topic area 'transitions' (Minichiello, et.al. 1990,p.113) were used. This is the method whereby relevant sections of the informants conversation to the topic area were selected by the interviewer, and used to re-focus the informants attention onto the topic area.

Other questioning techniques included ; 'funneling' - where the interviewer controlled the flow and type of information given - by concentrating the questioning on a specific topic area. By using the 'storytelling' approach - the informant was encouraged to express their views and experiences in their own language and way. Other techniques ; 'descriptive questioning' - enabled the informants to discuss their experience and place their own interpretations on these experiences. Questions which further elicited informants' feelings,

opinions, knowledge, and sensory aspects of their experiences were also used. Probing questioning enabled the researcher to verify certain information which the informant described and this was done by reflecting back the information to the informant by repeating the relevant statement or feelings.

3d) Data Collection.

The data collected included the transcriptions of the interviews conducted, as well as background research, and literature reviews on the topic, and field notes related to the interview. The fieldnotes, as described by Minichiello et.al., (1990), contained observations related to the interview process; i.e. the informant's environment, their facial and physical expressions - in relation to the questions asked during the interview. This enabled a broader picture of the informant and their lifestyle and social setting to emerge. The fieldnotes were recorded as soon as possible following the interview - so that information was neither missed nor forgotten. This facilitated the process of identifying and selecting relevant data, when themes and concepts had emerged, (Minichiello,et.al., 1990). Within the fieldnotes various files were produced ;

- A transcript file - which included the transcript of the interview.
- A personal file - relating the experience of the fieldwork.
- An analytical file - which focused on themes and concepts relevant to the research topic.

The Transcript file

This was a written account of the interview, transcribed from the tape recording, and included the informants' facial or physical actions in sequence with the questioning and flow of the conversation (Minichiello et.al.,1990).

The Personal File.

This was produced in the form of a diary or log - where the process of the research was recorded, and impressions and experiences expressed in a descriptive and unbiased form.

It also contained the researchers' impressions of the interview setting, and the appearances and reactions of the informants (Minichiello, et.al.,1990).

The process of approaching respective informants, and the experiences during the whole project was described, as well as a critical appraisal of methods and techniques used and their relative success or non-success.

The Analytical file

This consists of "*reflective notes on the questions asked in the course of the research and ideas emerging from the data*", (Minichiello,et.al. 1990, p.275).

This facilitated the process of determining the issues which may have been missed in an interview, and thus ensured these issues were covered in subsequent interviews with informants. It also enabled the researcher to focus on the research question, and reflect on issues which previous studies have highlighted.

The initial content of the analytical file included the establishment of themes and concepts related to informant's experiences of medication and treatment compliance regimes. As information collected in the file, key issues could be identified and emerging themes examined and compared, leading to the development of theoretical concepts (Minichiello, et.al., 1990).

3e) Data Analysis.

Minichiello et al (1990) state that "*The aim of data analysis is to find meaning in the information collected*" (Minichiello et al., 1990,p.285). The first stage in this process according to Minichiello (1990), involves 'coding the data' - that is, discovering themes and concepts, and developing propositions.

The second stage consists of refining themes and concepts. The third stage is the final report of the findings. In this research, themes were divided and sub-divided into conceptual categories - this ensured all the data was obtained before deciding which concepts and themes were relevant to the actual research question. During this process the research question was re-defined , and the 'grounded theory' approach developed in the theoretical perspective. As Miles and Huberman (1984) suggest "*Analysis during data collection lets the fieldworker cycle back and forth between thinking about the existing data and generating strategies for collecting new- often better quality - data*" (Miles & Huberman, 1984.p.49).

Interview Analysis.

The in-depth interviews conducted were included in the research study, and form a reflection of the informants beliefs, ideas, and feelings, in relation to the topic of medication and treatment compliance. The possibility of bias in the development of the analysis of the interview was considered, but, by taping and transcribing the interview this type of bias is less likely to develop when attempting to understand the informants' cognitive and conceptual beliefs in relation to health behaviour.

The Interviews

In the process of analysing the transcript, and with regard to the researchers' position as a nurse and interviewer, it was obvious that the informant may be providing a ; *"highly condensed and selective account"* of their experiences and may be very *"profoundly affected by what the respondent interprets the researcher as wanting to hear"* (May & Foxcroft, 1995, p.110). Furthermore, a possible key source of bias may be found in the *"power relationship between interviewer and interviewee"*, and that *"accounts of beliefs and behaviours that are produced in this context are the products of tasks internally directed within the interview"* (May & Foxcroft, 1995,p.110). With this in mind, a list of appropriate questions was prepared to be used appropriately during the interview, and this aimed to validate and verify the informants answers through probing techniques, and the issue of bias to some extent was addressed and removed.

Following the analysis of the first interview, it was realised further practice in interview techniques were needed, and that more concentration on the identification and expansion of relevant themes as they arose during the interview itself was necessary. To prepare for the interview a list of questions related to the topic of medication compliance was comprised, which was based on a literature search of other studies on the topic of compliance. During the course of the interviews this list of prepared questions was occasionally referred to - but many of the questions were found to be irrelevant to the informants' experiences and content of the subject matter discussed. It was also hoped that the taking of notes during the interview would be possible, which would assist in focusing questions, and verify answers given by the informant. However, it was obvious early on in the interview that this method was impractical as it detracted from the interviewers' concentration and listening skills.

The first informant was a young person with recent, short, and limited, exposure to the health system, as opposed to the remaining informants who had more chronic health conditions and therefore had experienced a longer interaction period within the health system, - and who may have developed more long-standing views and attitudes over time. The first informant was also able to express his views clearly and accurately, as the experience was still fresh in his mind, together with the feelings his experience had evoked.

Coding the data

The process of coding themes and topics which arose in the interview transcript, was to provide a systematic and thorough investigation of the data. The purpose was to code the information closely and refine the research question, and develop connections between the themes and concepts. Obviously, in such a small study sample of only 5 interviews, saturation point with regard to new information was not achieved.

For further analysis of the interviews and to facilitate the process of coding, it was decided to divide the contents into main themes and related concepts. Within the coding exercise, processes, actions, assumptions, and consequences were examined. This assisted the process of defining major activities and issues and enabled the researcher to discern connections between structures and events. From this perspective the concept of 'grounded theory' developed, where codes were separated into categories, and then defined analytically - which delineates their properties. According to Charmaz (1990) "*A major strength of grounded theory method is its open-endedness and flexibility*", (Charmaz, 1990, p.1168). This allowed ideas to form throughout analysis, enabled the researcher, to follow through leads and ideas as they developed.

In the analysis of the interviews by treating a term as a conceptual category the properties it contained were specified , and the conditions under which it arose noted, which relates to how it changes, a description of its consequences, and specifies its relationship to the other conceptual categories. By analysing 5 interviews, the researcher was able to compare different peoples situations, beliefs, behaviour, or accounts of the same type of event or issue. It was then possible to compare the circumstances under which the informants discovered and defined illness, how they felt, thought and dealt with the illness episode, and what advice and help they sought.

The following themes were identified with headings, and then divided into conceptual categories. Some of these categories have a theoretical basis, and others are based on the informants concepts. A theme will thus be identified with the letter T, and the conceptual categories discussed under each theme heading. The themes constitute wider issues and have a number of conceptual categories within them. The themes and conceptual categories are linked together and affect the ultimate outcome - that of non-compliance.

1. Decision to seek medical help. (T).

Here the informants recount their experiences of becoming 'patients' within the health system, and their reasons for seeking medical advice. These reasons are based on conceptual categories of the following ;

a) Expectations

This relates to the informants' expectations of the health system, and how their illness is treated. Which may in turn be based on their health beliefs.

b) Health Beliefs

This includes their own perceptions of their illness and its' seriousness; i.e. one informant knew she had heart problems and, as she considered the heart a vital organ, she felt she should seek and adhere to medical advice. Here the informant's own perceptions of illness, and its seriousness - results in their decision to seek medical help. This decision is grounded in his/her beliefs of health and what constitutes ill-health - which is related to their previous experiences, i.e one informant describes his back pain as ; *"Usually goes away by itself anyway"* .

Also related are the concepts of 'Lifestyle', and the concept that illness is caused from 'wrong doing' - i.e blaming the illness on his or someone else's mistakes (blaming concept). Another concept to consider here is one informant's comparison between the human body and a machine, where he explains that *"The human body is different to a machine in order that it repairs itself after a while"*. This analogy could be defined as given time the body heals itself, whereas a machine always needs help to reach the status of being repaired. Another informant did not consider his high blood pressure an important part of his condition and stated; *"lots of people have high blood pressure"*, and he therefore didn't consider his condition warranted medications to control his high blood pressure.

c) Pain

This was considered by all the informants as an important reason to seek medical attention. In this context , when describing his pain, one informant talks about having to *"Live with it"*. The degree and severity of the pain, and also its' location were also determining factors in seeking medical attention. For example, one informant considered 'chest pain' could be related to her heart condition and therefore required immediate attention.

2. Health professional and patient interaction (T).

The relationship the informants had with their doctors was an important feature in their decision to seek medical advice. All the informants considered the doctor as having superior medical knowledge and this was one of their reasons for seeking a medical opinion on their condition. However, on reflection the informants all reviewed the advice given to them by the doctor and 'weighed-up' their choices - which then led to their decision to 'non-comply'.

3. Non-compliance (T).

This theme has a number of conceptual categories which constitute the theme and interrelate and result in the outcome of non-compliance. The conceptual categories contained in this theme heading are described below ;

a) Lack of information and explanation.

Three out of the five informants expressed their frustration at not being given sufficient explanations regarding their illness, the medications they were prescribed, and the suggested treatments offered. One informant expressed his frustration when he was treated "*like an object*" by health professionals, and goes on to say "*I'm not too stupid to understand certain principles....they should explain a bit moreand not just leave you in the dark*" .

This also links to the concept of individuality.

b) Individuality.

Three of the five informants stated they were treated as not being intelligent enough to understand explanations of their condition or principles of their treatments. When one informant was questioned further and asked why he thought he was not given adequate

information on his condition his response was ;"Because they might think I don't understand it".

Further interviews with patients of varying ages, and gender differences may show a change in this attitude, as the two informants who had not expressed dissatisfaction through lack of information were the two elderly informants, who had also previously stated that they considered the doctor as an 'expert' and felt they did not require further information on their condition. This also links with the doctor-patient interaction theme, and issues of autonomy, equality, power and control - where the doctor is considered the expert and beyond questioning (this is further discussed in the section on the theme of interaction).

c) Quality of care.

One informant became non-compliant with treatment following his experiences in the x-ray department where he was not given any information regarding the affects of radiation on his body, and even had to threaten to leave in order to be given a "lead skirt" to cover and protect his "vital parts" . As these procedures are subject to patient consent issues, the informant is in the position of not being able to give his consent based on his lack of information, therefore the issue of informed consent is an important one and links also to quality of care issues.

d) Side-effects of treatment.

All of the informants (except 1) were aware of the side-effects of the medications they had been given. They then 'weighed-up' the pros and cons of taking or not taking the medications - which was dependent on their desired health state. One informant was non-compliant with anti-depressants as they made him "too drowsy". Another decided not to take pain killers for his back pain due to their "horrible" side-effects and decided it was preferable to "live with the pain", rather than suffer the consequences of the side-effects of

the tablets. Another informant was non-compliant with an anti-arthritis medication as she found the side-effects of the medication (indigestion) intolerable.

The theoretical concept titled "the explanatory social model" (Charmaz, 1990) relates to one informant's understanding of his illness and associated treatment. In this context he discovers that the tablets he has been given by the doctor do not "*help my back*", but are "*Just something against the pain*". This is unacceptable to him as appropriate treatment for his back and therefore he decides to 'non-comply' with the medication and decides to '*live with the pain*'. This is a recurring concept in previous studies of non-compliance (Donovan & Blake, 1992).

e) Weighing-Up.

All of the informants expressed the desire to choose their health care options, and 'weigh-up' their choices. One of the informants' decided not to comply with a suggested breast screening procedure as she felt it was ; "*not necessary at my age*". This concept also links to the concept of pain , where one informant decides the pain in his back is preferable to the side-effects of the tablets. To help choose this course of action the informant draws on his previous experiences of backpain, which he describes as ; "*Usually goes away by itself anyway*", here it is assumed tablets were not required in previous episodes of backpain.

f) Control.

The informants' decisions to non-comply may be linked to their need for control in the choices available to them, and ultimately their decision-making process. This is highlighted in one informant's account of his father's illness, where his father sought medical attention for a heart problem and was given the choice to lose weight, change his diet, or take medications for the rest of his life. The informant approves of this choice, and

would prefer to be given the option of deciding for himself what treatment is preferable and acceptable to him. Another example relating to control over health status is expressed by one informant who states ; *"It's my body, my health and everything, and they just treat you like a car or something that you repair that doesn't have an own will or consciousness"*. He goes on to say that doctors should *"explain a bit more and not just leave you in the dark"*. This links also to the concept of lack of information, and also to the relationship and interaction between doctor and patient.

g) Experimentation.

All the informants had experimented with reducing their medication dosages, but none had increased their medications. During one interview the informant initially denies experimenting with medication dosages, but following direct questioning by the researcher, he admits to experimenting with lower doses of medication but states he would not consider taking more than the prescribed amount of tablets. This concept can be found in previous studies relating to medication compliance, where data shows that patients often experiment with prescribed dosages - often because they prefer to manage their conditions with less medications rather than increasing their doses of tablets (Donovan & Blake 1992, Baker & Napthine 1994). Three of the informants expressed a dislike of becoming dependent on drugs, and stated they preferred to manage their conditions with as few medications as possible. This also relates to research which indicates that non-compliance increases when more than 3 drugs at a time are prescribed.

h) Harm.

One informant decides to accept the G.P's suggestion of an x-ray of his back, and relates his feelings regarding this as *"Why not, give it a try ?"* . This indicates a feeling of what has he got to loose . However, when he arrives at the x-ray department he reflects on his choice

more closely and is happy to have one x-ray, but is annoyed to find out that three x-rays need to be taken. Here he is in a dilemma, as he is aware of the dangers of x-rays which "*might cause cancer or whatever*", but he has already made the decision to have the x-rays, and so he continues with the treatment and states he "*Wasn't too happy about that*".

This relates to possible non-compliance with further x-rays, which the informant considers, and also relates back to lack of information regarding his choices. This decision process is highlighted later during our discussion relating to antibiotics. Here the informant is aware of the mode of action of antibiotics, and realizes the importance of completing a course, and then, armed with enough information on the subject, he is able to make a decision based on informed choice, and hence is more likely to adhere to medication regimes.

i) Market Forces.

The issue of cost is apparent in all of the interviews. All of the informants are willing to pay for their treatment if they consider the treatment necessary. Their willingness to pay also depends on their perceived seriousness of their condition for example, one informant states ; "*I would pay a thousand dollars for an eye operation*", and goes on to say "*if its twenty bucks for something against a cold which is not very serious I probably wouldn't pay that*".

One informant considers that the doctor's failure to give him adequate information regarding his condition is also related to monetary influences - where the doctor may be concerned with seeing as many patients as possible to earn more money - this limits his consultation time and therefore explanation time ; "*I guess they just want to rush patients through as many as possible per day to get as much money as they can*".

j) Trust.

One of the informants' trust in his G.P's motives is affected when he describes the doctors as "*making lots of money*" when they prescribe certain drugs. This could affect the relationship between a doctor and his patient, if the patient only thinks that he is given medication so the doctor can gain money from the pharmaceutical industry. This is obviously a concept one of the informants has considered and also links to the previous concept of market forces.

k) Autonomy.

During one interview the informant refers to the doctors being "expert", and therefore the patient should be able to trust his judgment. Previously, however the same informant had stated that he is a "*thinking human being.....and I don't like anyone to tell me what to take and not knowing what it is*". From this statement two issues arise, that of lack of information, and being treated appropriately - that is being given appropriate explanations. From this it seems the informant respects the doctor as being more knowledgeable in the area of medicine but he also expects to be treated with respect and in relation to his level of intelligence.

The interaction one informant describes with his G.P terminates with the informant stating that the G.P "*let me go*". Here it seems the informant feels that he has been detained. It could be argued that he felt as if he was in a subordinate position and that he saw the G.P in a more dominant role and in control of the consultation interaction episode.

l) Setting.

In relation to the above incident it is possible that the setting where the interaction has taken place might influence the doctor-patient interaction. In this context it is possible that the x-

ray department, and G.P's surgery is not conducive to effective interaction as it is not equal territory but the health professionals' environment.

Iatrogenesis (I).

This theme is relevant to the informant's feelings regarding the dangerous side-effects of both the medications they were given, and the treatment (i.e. x-rays) suggested. One informant stated that breast screening was "*unnecessary at my age*" (she was in her eighties) and felt the doctors' suggestion of screening was inappropriate and a "*waste of money*".

SUMMARY OF ANALYSIS.

In choosing this method of research I agree with the authors May & Foxcroft , who state that qualitative methods ; "*re-instate context and emphasize meaning*", and that "*Qualitative data collection and analysis can be seen as an attempt to be 'holistic' in relation to research practice*" (May & Foxcroft, 1995,p.1).

Following analysis of the interviews various issues arise which support the findings in previous research studies indicating that ;

1) The provision of improved dissemination of information regarding medications and treatments and patients' own disease status, would enable patients to make informed decisions about their treatments. With increased control over their health status patients are more likely to actively participate in treatment and medication protocols - which in turn leads to an increased likelihood of 'compliance'.

- 2) Health beliefs and attitudes together with expectations of the health system affect a person's initial desire to seek and adhere to medical advice.
- 3) The interaction between health professionals and patients in regard to the setting in which the interaction occurs, also affects a patient's decision to adhere to medical advice and treatment. Also the attitude of the health professional towards a patient, the communication, control, and autonomy strategies which the health professional projects, all affect a patient's decision to control their own health status. This is a situation to which most patients ascribe, but often does not occur in the doctor-patient interaction setting.
- 4) Patients require a more participatory role in deciding medication and treatment regimes which consider their own health beliefs and lifestyle practices.
- 5) There is a need to treat each patient as an individual, and prescribe relevant treatment and medication regimes based on each patients' level of knowledge and understanding, in order to achieve a mutually agreed health care regime.

Consequences for future patient care.

Generally, this research proved to be an informative process in relation to the researchers' profession in Community Nursing. Through this process an increased understanding of the prescribing of treatments from the patient's perspective has emerged, and it is hoped that the development of the above findings into assessing and planning patient care regimes will be an important outcome of this research on patient care. This includes increased participation for patients in regard to planning care which is conducive to their beliefs and lifestyle, and also includes improved explanations and information on treatments and medication regimes.

Appendix A.

Dosette Box - A container used for the dispensing of medications. It can have up to four compartments per day for 6 hourly medications, and allow for medications to be stored for up to one week. Medications are placed in the appropriate compartments and dispensed at the appropriate time. It is especially useful for patients with short-term memory loss problems.

Appendix B.

RESEARCH STUDY INTO MEDICATION AND TREATMENT REGIMES.

INFORMATION FOR PARTICIPANTS.

You are invited to take part in a study into medication and treatment regimes which have been prescribed to you by your doctor, or other health professional.

The study is being conducted by ; Melissa House, who is a Community Nurse from Sydney Home Nursing Service, and who is conducting the study as part of her Masters' Degree in Community Health at Sydney University.

The aim of the study is to determine patients' own views, experiences, and beliefs, concerning the medications and treatments they may have been prescribed, and therefore gain a patients' perspective of their treatments and how this impacts on their attitudes and lifestyle. This will enable health professionals to gain an important understanding of patients' own views on medications and treatment regimes.

Your participation in this study is entirely voluntary ; you are not obliged to participate, and if you do participate you are able to withdraw at any time. Whatever your decision, it will not affect your nursing treatment or relationship with nursing/medical staff.

All aspects of this study, including the results, will be strictly confidential, and will not be revealed to any nursing or medical staff looking after you. A report of this study may be submitted for publication, but individual participants of the study will not be identified.

If you agree to participate you will be asked to take part in an interview with the researcher (Melissa House). The interview will be conducted at a location and time suitable to you. The interview will last approximately one hour, and will be tape recorded. In the interview you will be asked some general questions regarding your health, and any medications or treatments you may have had, or are currently taking.

Prior to your participation in the interview, you will be asked to read and sign a consent form.

If you would like further information at any stage, please feel free to contact **Melissa House** on (02) 9909 8331 (Home), or (02) 438 1592 (Work).

This information sheet is for you to keep.

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