

CHAPTER 5

5.0. PREDICTORS AND REASONS FOR NON-COMPLIANCE

The predictors and reasons for non-compliance appear to be multiple and varied. Often several reasons appear to operate in the non-compliance of a single individual. Novaes et.al. (1999) in discussing supportive periodontal therapy suggest that compliance is a very complex matter and findings from individual studies cannot be generalized. Similarly, O'Hanrahan and O'Malley (1981) conclude that the factors concerned in failure to comply with therapeutic regimens are complex. Rarely does a patient default for one single reason but rather because of a multiplicity of reasons that interact to produce a state of affairs in which compliance is difficult.

There are no simple answers to the etiology of non-compliance and there has been an increasing body of research in this area in all aspects of medicine. Even in single studies several factors have emerged (e.g. Randolph and Frazer 1999).

5.1 Personal Beliefs and Distortions

There are many myths or cognitive distortions about various medications and forms of treatment and even of the illnesses themselves of which medical professionals are not always aware (Butler et.al., 1999). Britten (1994), feeling that little attention had been paid to this issue and that such ideas might well have relevance for understanding

non-adherence to medication, did a qualitative study in a general practice population on patients' ideas about medicines. The data revealed that on the one hand a great deal of medicine taking was taken for granted (by the patient) and on the other hand that patients had many fears and powerful negative images of medicines.

It is interesting to quote Stimson (1974) on this subject:

" Now where do people get their ideas about the use of medicines? Seeing the patient in the formal setting of the consultation the doctor may be led to believe that he is the main source of people's ideas about medicine, that they are passive acceptors of his instructions. He may be the source of ideas, but he is by no means the only source." (Stimson, 1974, p. 101).

He goes on to show how medicines are discussed with members of the family, with friends and neighbours, and often drug taking decisions are made on the basis of this, often contrary to what the doctor advises. Is Stimson (1974) perhaps suggesting that the 'next door neighbour' who had, she felt, a bad reaction to a medicine that looked somewhat similar' might in fact have more influence on whether the patient will take the medication than the doctor? A recent study confirms Stimson's (1974) suggestion that the doctor is definitely not the sole influence on the patient.

Mills and Davidson (2002) found something similar in their study of cancer patients' sources of information. Hospital consultants were found to be the primary source of information for the vast majority of patients. However in terms of quality of information, they fell to third

place. They felt this might be due to conflicting advice or a dismissive attitude or lack of time to discuss real problems. Family and friends were sources of information for 75% of patients and seen as an excellent source by 61% of patients. Often the physiotherapist was seen as the best source. Media sources were not as highly relied on as might be imagined. Reading material is often too difficult for them. The Internet, though used by few patients and depending on computer literacy and accessibility is considered an excellent source, though, as will be seen later, a great deal of misleading information is provided.

Heurtin-Roberts and Reisin (1992) point out that problems in compliance with treatment and illness management have frequently been traced to differences between patients' explanatory models of illness and the biomedical model. Mere attendance of medical services does not necessarily imply full acceptance of the biomedical model. This would be especially true in South Africa where Traditional Medicine is an important factor. Gupta, Sen Mazumdar, Gupta, Sen Mazumdar and Gupta (1998) found many barriers to compliance in bronchial asthma in India. These included the presence of superstition, misconceptions, ignorance and strong bias against the use of metered-dose inhalers.

Butler et.al., (1999) found some persistent myths about hypertension which were found to interfere with its diagnosis and treatment . Belief and trust in conventional medicine was strongly associated with adherence to treatment in non-insulin-dependent diabetes mellitus patients (Garay-Sevilla, Malacara, Gonzalez-Parada and Jordan-Gines, 1998). In the same vein, Altice, Mostashari and Friedland (2001) found low adherence because HIV patients did not trust the doctor nor the medicine. (see also Murphy , Greenwell and Hoffman , 2002).

Andro, Bouhnik , Soletti , Bertholon , Moatti , Rossert and Spire (2001) found that some patients did not adhere because they did not believe in the treatments' effectiveness.

Murphy et. al. (2002) in their study of AIDS diagnosed women, found non-adherence to be connected with such factors as: perceived stress; poor self-efficacy to stay with treatment; and poor outcome expectancies regarding the benefits of following the treatment regimen.

On another level Holmes and Pace (2002) found that in HIV/AIDS patients' current perceptions about life expectancy indicated that most respondents thought they would live many years, many believing they would live well into old age. Seropositive individuals self reported optimistic beliefs about their prognosis and were significantly more likely to report medication and safe sex adherence.

5.1.1 Distortions about particular groups of medicines

Woller, Kruse, Winter, Mans and Alberti (1993) found that, in patients with bronchial asthma, there were often irrational fears of cortisone medication beyond justified worries about side-effects. They felt that a cortisone image which involves overemphasizing the threatening aspects of cortisone, often underlies non-compliant illness behaviour. Studd et al. (1996) felt that poor compliance with Hormone Replacement Therapy (HRT) may arise from a lack of awareness of the benefits of HRT, or from a number of common misconceptions, particularly the idea that HRT is 'unnatural', and will cause weight gain, cancer, or unpleasant side effects. Gomes M da and Maia Filho H de (1998), working with epileptics found that 44% said to be afraid of becoming addicted to the medicine.

Lichtigfeld and Gillman (1998), working in South Africa, found that there was a view among both the lay and medical audience that antidepressants were addictive. This resulted in resistance to taking the medicine and poor compliance in those who initiated treatment.

Burns (2000) describes and responds to eight myths which people hold about anti depressants:

1. "If I take this drug, I won't be my true self. I'll act strange and feel unusual." Burns (2000) points out that many patients report that they feel more like themselves after they take an antidepressant medication.

2. "These drugs are extremely dangerous".

Burns (2000) comments that adverse reactions are rare and can usually be safely and effectively managed when the patient and his/her doctor work together as a team.

3. "But the side effects will be intolerable."

Burns (2000) counters that the side effects are mild and can usually be made barely noticeable by adjusting the dose properly.

4. "But I'm bound to get out of control and use these drugs to commit suicide."

Burns (2000) points out that if the patient feels suicidal he should not have a lethal dose in his possession and when the drug begins to work the patient will feel less suicidal.

5. "I'll become hooked and addicted, like the junkies on the street. If I ever try to go off the drug, I'll fall apart again. I'll be stuck with this crutch forever."

Burns (2000) counters that, unlike some other drugs, the addictive potential of antidepressants is extremely low.

6. "I won't take any psychiatric drug because that would mean I was crazy."

Burns (2000) counters that antidepressants are given for depression, not for craziness.

7. "But other people are bound to look down on me if I take an antidepressant. They'll think I'm inferior."

Burns (2000) points out that other people will not know they are taking an antidepressant unless they tell them.

8. "It is shameful to have to take a pill. I should be able to eliminate the depression on my own."

Burns (2000) mentions that an antidepressant may give the person that little edge that he/she needs to cope in a more productive manner. It is clear that many of these beliefs also extend to medications as well, other than antidepressants.

The anti-HIV drug combinations, known as highly active antiretroviral therapy (HAART) have proven to be highly effective weapons against HIV. However, thus far, these treatment advances require that patients be able to adhere to complicated treatment regimens for long periods of time.

Interruptions in medication adherence permit the virus to resume its typical rapid replication.

"Therefore medication adherence has now become a critical issue for HIV/AIDS care."

(Murphy, Wilson, Durako, Muenz, and Belzer, 2001, p. 27). Poor adherence to treatment can lead to the emergence of drug-resistant viral strains that need new combinations of drugs or new drugs altogether (Harries, Nyangulu, Hargreaves, Kaluwa and Salaniponi, 2001).

Walsh, Horne, Dalton, Burgess and Gazzard (2001) found that patients reported multiple reasons for missing doses and the range of reasons increased with declining adherence. Spire, Duran, Souville, Leport, Raffi and Moatti (2002) found people to be non-adherent because of the belief that HAART was toxic or ineffective.

There are many misconceptions about taking medicine for the treatment of HIV/AIDS. In South Africa it is widely believed that anti-AIDS drugs accelerate death or make people sick with AIDS. In South Africa, also, there are very large doubts in government circles as to whether AIDS drugs should be used at all (Schuklenk, 2003). This is perhaps similar to the situation in America 20 years ago where the severity of AIDS was not yet recognised. Shilts (1987) wrote a book, "And the Band Played On", describing the initial inertia on all levels. He says, "By the time President Reagan had delivered his first speech on the epidemic of Acquired Immune Deficiency Syndrome, 36,058 Americans had been diagnosed with the disease; 20,849 had died" (Shilts, 1987, p. 596).

To help understand why people of ethnic minority groups tend to be less likely than European Americans to take medication for HIV, Oggins (2003) obtained narratives from 62 multiethnic

HIV-positive individuals (ages 16-53 yrs). These narratives were coded for mention of taking medication for HIV and the reasons for not doing so. Some recovering drug users expressed concern about ingesting synthetic medication or considered medical regimens as constraining as a drug addiction. Some in the sample also thought antiretroviral medications were toxic, especially when taken in combination. Others thought they should wait until they were ill before taking medication to prevent opportunistic infection.

5.1.2 The Diagnosis

The diagnosis is accepted by the patient in various ways, being slotted, as it were into the patient's conglomerate of real knowledge, distorted fears and beliefs, advice by even more biased, less knowledgeable neighbours, relatives and friends. King (1983) puts this very clearly:

"It has become evident that different patients see health and illness in many different ways. A patient will not always accept an objective medical explanation or diagnosis at face value. This acceptance may be coloured by many personal beliefs held by the patient. It is motivation that translates the health belief into behavior and which therefore needs to be identified by the doctor." (King, 1983, p. 114)

Hausen (1999) studied the first contact between asthma-patients and the family physician. They found that the diagnosis of "asthma" was often followed by treatment cessation. Unfortunately it is not clear which factors operate in this study.

Becker (1985) comments on the patient's often distorted reaction to the diagnosis. He found that of all the patient health beliefs, the one that seemed to surprise practitioners most is acceptance (or non-acceptance) of the diagnosis.

Why would a person seek out and subject him or herself to expert examination and consultation (often costly and uncomfortable) and then reject the professional's conclusions? According to Becker (1985) at least three kinds of situations can undermine belief in diagnosis:

"First, the patient may possess powerful, well-defined (albeit scientifically erroneous) health beliefs that conflict with the physician's assessment of the problem (e.g. 'I can't have high blood pressure because I'm not the nervous type'). These beliefs have multiple origins (e.g. from cultural subgroups, parents beliefs, prior experiences with an illness, misinterpretation of factual information, or acceptance of erroneous information from nonmedical sources). The existence of a great variety of problematic health beliefs is well-established." (Becker, 1985 pg. 5)

Secondly, all kinds of incidents occur during a consultation which undermines the patient's belief in the diagnosis, especially if the patient feels that the doctor is not 'hearing' him or her and paying attention to the presenting symptoms. Often the patient has withheld details or a major part of the problem and continuing to withhold it he/she feels the diagnosis could not be complete. Thirdly, patients sometimes reject a diagnosis too painful to accept. They often react initially to a life-threatening illness by denying they have it (Becker, 1985).

In particular relation to this study, a diagnosis of cancer often is seen as synonymous with death. For instance, Levy (1999) points out that the word 'cancer' has different meanings for different people. In general, it is synonymous with fatality, either imminent or in the foreseeable future. How each person perceives and attributes meaning to this personal experience, varies according to idiosyncratic factors. These factors are constituted by each individual's unique internal make up and by external influences and it is the combination of the multiplicity of factors that bring about the personal attributions of meaning for each individual.

5.1.3 Self (Mis) perception of success

Non-compliance is often the result of an error in judgment, where the person is convinced he is cured or does not need the medicine (Al-Shammari et.al. 1995). Examples are: Mulet Pons, Sarrion Ferre, Barea Montoro, Marin Rueda, Blanquer Gregori and Melchor Penella (1995) in the non completion of the influenza vaccination; Cohn and Pizzi (1993) with allergen immunotherapy; Thomas (1994) in propionic acidemia patients and Brookoff (1994) with doxycycline therapy for outpatient treatment of pelvic inflammatory disease. Sunakawa et.al. (1995) studied the rational use of oral antibiotics for pediatric infections. One of the reasons for unsupervised self-discontinuation was that the parent or guardian judged the infection to be cured.

There is also the matter of the perception of the risks involved in not following through with treatment. Dujardin et.al. (1995) found that in the referral of risk patients in antenatal care the

geographic accessibility of the hospital and the patient's perception of the risk status were the two most important factors determining the compliance rate.

A lack of symptoms in a chronic illness makes it difficult for many patients to be compliant. Bobbio, Riccardi, Bongioanni, Orzan and Brusca (1994) found that the absence of typical angina was predictive of non-compliance in following the clinical indications prescribed after coronary angiography. Balazovjech and Hnilica (1994) found that feeling of well-being without therapy was one of the principal reasons given for irregular drug taking in hypertensive patients. On the other hand it seems to be true that the patient who has had experience in realising the seriousness of his/her condition tends to be more compliant. Rand et.al. (1995), in studying lung function, found that the best compliance was found in participants who had more severe airways obstruction.

5.1.4 The Health Belief Model

During the early 1950's, a group of social psychologists working at the United States Public Health Service, developed a theoretical framework for explaining the likelihood of an individual's undertaking a recommended preventive health action, for example, obtaining immunizations and participating in screening programs for early detection of asymptomatic disease (Becker, Marman, Kirscht, Haefner, Drachman and Taylor 1979). According to the health belief model designed by Becker et. al. (1979), a patient will comply when he/she believes that the diagnosis is correct, the illness can result in serious harm or injury, or the recommended therapy reduces risk. In other words, the vulnerability to disease is recognised

by the patient who knowledgeably weighs the cost of complying (i.e. cost, time discomfort, inconvenience, and so on) against the potential cost of risk taking (Anderson & Kirk, 1982).

"A sizable body of published data now exists that shows positive correlations between patients' compliance and their health beliefs. Three important implications have been drawn from these data. First, the data have been interpreted as indicating that a patient's compliance is largely determined or caused by his health beliefs. Second, the implication has been drawn that physicians might be able to identify non-compliant patients by inquiring into their patients' perceptions of their illness and treatment regimen. Finally, it has been speculated that compliance might be improved by strategies designed to modify health beliefs and perceptions." (Taylor, 1979, p. 103)

Kessler (2003) points out that patients tend to remember details given to them by their doctor more easily and accurately when they fit in with their own health beliefs and forgetting much of what is said that they don't "agree" with.

Taylor (1979) felt that health beliefs related to hypertension and its treatment that were assessed before the initiation of drug treatment for hypertension did not predict compliance six- and twelve-months later. However, health beliefs expressed six months after the initiation of treatment were found to be consistent with compliance measured at the same point in time and also predictive of subsequent (twelve-month) compliance. He felt that it was likely that health beliefs, instead of preceding and determining compliance behaviour, developed along with compliance behaviour as a result of experience with treatment gained by patients in the

early weeks of months of therapy, thus bringing a very different perspective.

Irwin, Millstein and Ellen (1993), however, found that the only construct of the Health Belief Model, found to be significantly associated with appointment keeping in adolescents, was the number of potential negative outcomes resulting from non-compliance perceived by the subject. However a confounding factor is that adolescents are usually required to conform to medical treatment regimens required by their parents, highlighting problems particular to this age group.

Imanaka, Araki and Nobutomo (1993) studied the effects of patient health beliefs and satisfaction on compliance with medication regimens in ambulatory care at general hospitals. Their results indicated that self-efficacy regarding compliance behaviour, perceived threat to health, patient satisfaction with care, severity of illness scored by the physician and sex and age had significant effects on medication compliance.

5.2 Doctor-patient Communication

Doctor-patient communication is a very strong factor in patient compliance or non-compliance. Though other health workers often play a major part, the doctor is the focus of a patient's health behavior and relationship to his/her disease (O'Hanrahan and O'Malley, 1981). However as Francis, Korsch and Morris (1960) comment, medical care is becoming increasingly fragmented and complex and the warmth of a long-term association with a single physician has become a luxury for a few.

Haag and Gerber (1993) in their studies on the drug therapy of pain-control, found that non-compliance indicated a disturbed doctor-patient relationship. Moskowitz (1996) found similar results. The patient in pain needs added reassurance from the doctor as to the nature and reason for the pain and the assurance that it can be handled, and that it is 'normal' for the condition.

Bour, Blanchard and Segal (1993) studied patients with primary open-angle glaucoma. According to their survey, one of the principal causes of poor compliance was a poor doctor-patient relationship. Schoni, Horak and Nikolaizik (1995) studied compliance with therapy in children with respiratory diseases. They concluded that compliance is based on the efficacy of the drug itself and the attitude of the physician.

"One of the basic problems in the relationship between a doctor and a patient is that the expectations that each has for the other are rarely congruent. If this is the case, then the doctor can no more assume that the patient will comply with his directives than the patient can assume that the doctor will provide him with all the things he expects: assurance, explanation, comfort and cure." (Davis and von der Lippe, 1965, cited in Davis, 1966 p. 1037).

Francis, Korsch and Morris (1960) found that the extent to which patient's expectations from the medical visit were left unmet, lack of warmth in the doctor-patient relationship, and failure to receive an explanation of diagnosis and cause of the illness were key factors in non-compliance. Davis (1966) found that when doctors failed to convey the significance of the regimen to the patient, there was a reciprocal failure on the part of the patient to comply with

the doctor's advice. Doctors have tended to blame the patient for non-compliance, seeing them as difficult and rebellious. Davis (1966) found that sixty-one percent of the junior physicians and 67 percent of the senior physicians he studied felt that non-compliance could be attributed to a patient's uncooperative personality. He comments that in answer to the question "What can a doctor do about non-compliance?" the junior doctors responded : To influence an uncooperative patient, he/she would first explain and try to persuade the patient, and if that failed he would either 'get tough' or refer the patient to another doctor. Implicit in this discussion, the failure of the patient to accept uncritically the authority of the practitioner, is the problem of controlling patient behaviour.

Some significant comments were made by Butler, Rollnick and Stott (1996) about this. They suggest that instead of seeing resistance to change as rooted entirely in the patient, it should be viewed as stemming partly from the way clinicians talk to patients. Another aspect is the physician him/herself and the schedule he/she operates under and whether this gives him/her time to be the caring, concerned and educative doctor.

5.3 Psychiatric Conditions

Often perception and judgement are impaired in certain psychiatric conditions (e.g. depression, paranoia, hypochondriasis, somatoform disorder, to mention a few) which are bound to affect compliance (Anderson and Kirk, 1982). Psychiatric patients, particularly those with schizophrenia, paranoia or personality disorders, tend to be low compliers (Haynes, 1979).

Anxiety and stress also show an influence on compliance, generally, but not always, in a negative direction. An interesting result was found by Bille (1981) who found that patients in general with either high or low anxiety showed complications in complying. This would indicate that a patient should have a basic amount of anxiety to be compliant. MacLean and Lo (1998) found that in the non-insulin-dependent diabetic, failure to comply was a function of a syndrome of stress, chronic and transient mental distress. Molassiotis, Nahas-Lopez, Chung, Lam, Li and Law (2002) mention anxiety as a strong predictor of non-adherence, and treatment for this should be offered to patients, increasing not only adherence rates but also improving quality of life.

Sternhell and Corr (2002) did research to determine whether psychological morbidity is associated with poor compliance with antiretroviral medication in HIV-positive subjects. They found that forty-four per cent of subjects were identified as suffering psychological disorder. Expressed skepticism about medication and previous use of psychotropics was also associated with poor adherence.

Kalichman and Rompa (2003) found that people who were currently taking antiretroviral medications and missed at least one dose of their medications in the past week scored significantly higher on a hopelessness scale and reported more current use of marijuana. People who had been non-adherent also reported significantly more sexual behaviour that would place them at risk.

5.3.1 Depression

Recent studies are showing a substantial and consistent relationship between adherence to antiretroviral regimens and depression (Starace, Ammassari, Trotta, Murri, De Longis, Izzo, Scalzini, d'Arminio Monforte, Wu and Antinori, 2003). Similar findings are reported by a number of authors (Spire, Duran, Souville, Leport, Raffi and Moatti, 2002; Carrieri, Chesney, Spire, Loundou, Sobel, Lepeu, Moatti, Boirot, Bouhnik, Cassuto, Dellamonica, Dujardin, Duran, Gallais, Gastaut, Lepeu, Marimoutou, Mechali, Moreau, Negre, Obadia, Poizot-Martin, Pradier, Rey, Rouzioux, Tremolieres, and Vlahov, 2003). Holzemer, Corless, Nokes, Turner, Brown, Powell-Cope, Inouye, Henery, Nicholas and Portillo (1999) found that HIV-positive clients with higher symptom scores, particularly depression, were more likely to be non-adherent to medication, not to follow provider advice, and to miss appointments.

An interesting study was done by Carney, Freedland, Eisen, Rich and Jaffe's (1995) whose work suggests that depression may explain the increased risk of medical morbidity and mortality found in older medical patients. They studied patients over the age of 64 years with coronary artery disease. All patients were prescribed a twice-per-day regimen of low dose aspirin to reduce their risk for myocardial infarction. Medication adherence was assessed for 3 weeks by an unobtrusive electronic monitoring device. Depressed patients adhered to the regimen on 45% of days, but non-depressed patients, on 69%.

In a study of the psychological factors associated with poor compliance with treatment in asthma, Bosley, Fsbury and Cochrane (1995) found that the non-compliant group had a higher

score for depression than the compliant group. In a study of treatment compliance, following kidney transplantation, Kiley, Lam and Pollack (1993) found that depression and locus of control attributed to powerful others were some of the factors associated with non-compliance. Edinger, Carwile, Miller, Hope and Mayti (1994) did a study on compliance with therapy for sleep apnea. They found, among other things, that eventual compliers scored lower on a depression scale prior to treatment than did the non-compliers. To investigate interrelationships between psychological, medical, and compliance factors, hemodialysis (HD) patients were studied with the Beck Depression Inventory. It was found that patients with mild depression were more likely to skip treatments (Kimmel, Peterson, Weihs, Simmens, Boyle, Verne, Umana, Veis, Alleyne and Cruz, 1995).

Simoni, Frick, Lockhart and Liebovitz (2002) found that patient claims that they "forgot" (50%) and "felt worse" (46%) were the most common reasons for missed doses. Need for social support was positively correlated with acknowledged non-adherence and that this relationship was mediated by self-efficacy and depressive symptomatology.

5.4 Personality Factors

The study of compliance reveals various personality factors which have been found to be significant or important. Some of this relates to compliance being related to socially compliant or acceptable behavior and non-compliance relating to behavior which is less socially compliant or acceptable. Schoen (1993) discusses the resistance to health, when the mind interferes with the desire to become well, which can lead to medical non-compliance.

The findings of Penedo, Gonzalez, Dahn, Antoni, Malow, Costa and Schneiderman (2003) suggest that personality traits are associated with HIV-specific quality of life on the one hand, and that HIV-specific quality of life is related to HAART adherence on the other. Problems with adherence levels with antiretroviral medication were found to be related among other factors, such as to stress and lack of motivation (Puigvents, Riera, Delibes, Pearanda, de la Fuente and Boronat, 2002). Pinheiro, de-Carvalho-Leite, Drachler and Silveira (2002) found that self-efficacy was the most important predictor of adherence to antiretroviral medication. Similarly, Taal et al. (1993) working with patients with rheumatoid arthritis had found compliance to be related to the patient's self-efficacy expectations about coping with arthritis.

Christensen and Smith (1995) found that conscientiousness was significantly associated with adherence to the medication regimen in renal dialysis patients. Similarly, Hershberger, Robertson and Markert (1999) did a study on personality and appointment-keeping adherence in cardiac rehabilitation. The differences between compliant and non-compliant patients were significant on the "Socialization" (acceptance of rules and regulations) and "Good Impression" scales (desire for others to have a favorable impression of oneself). Barglow, Hatcher, Edidin and Rossiter (1984) found three traits to be highly relevant to compliance behaviour in the diabetic patient, these being intellectual efficiency and planning, sense of responsibility for self, and perception of socialization capacity. Earl (1991) also studied compliant and non-compliant diabetic patients. The compliant patients had a more positive degree of emotional adjustment, less perceived stress, greater tolerance for ambiguity and greater cooperation with the medical staff. As can be expected from the above, Anderson and Kirk (1982), found that hostility toward authority figures, tends to decrease compliance.

A somewhat unusual approach is given by Bursten and D'Esopo (1965) in an article entitled, 'The Obligation to Remain Sick'. The authors argue : "In more than a few cases, what appears as deviant or defiant behaviour may really be compliant. There are a significant number of instances where family members neither expect the patient to get well nor do they genuinely desire improvement. In these situations we should not speak of the obligation to want to get well but rather of the obligation to remain sick." (Bursten and D'Esopo, 1965, p. 402-403)

5.5 The Death Instinct

Freud (1920/1962) was the first theorist to introduce the concept of the death instinct. He described an unconscious drive toward self destruction inherent in everyone. This could manifest in various forms such as self mutilation, self denial, depression, aggression. destructive impulses towards others, and, in extreme cases, suicide.

Menninger (1966) discusses Freud's further assumption that the life and death instincts (which Menninger calls the constructive and destructive tendencies of the personality) are in constant conflict and interaction just as are similar forces in physics, chemistry and biology. He raises the question as to why everyone does not decide to die, and argues thus: "In other words, why does the wish to live ever, even temporarily triumph over the wish to die?" (Menninger, 1966, p. 5)

Menninger (1966,) writes that these forces, originally directed inward become directed outwards as the person grows and develops: "But no one evolves so completely as to be

entirely free from self-destructive tendencies; indeed, the phenomena of life, the behaviour peculiar to different individuals, may be said to express the resultant of these conflicting factors. A sort of equilibrium, often-times very unstable, is achieved and maintained until disturbed by new developments in the environment which cause a re-arrangement with perhaps a quite different outcome. On this basis we can understand how it can be that some people kill themselves quickly and some slowly and some not at all, why some contribute to their own deaths and others withstand valiantly and brilliantly external assaults upon their lives to which their fellows would have quickly succumbed."(Menninger, 1966, p. 6) This often takes place automatically and unconsciously.

5.6 Locus of Control

Jaspars, King and Pendleton (1983) discuss the concept of locus of control, an attempt to characterise individuals in terms of the extent to which they believe they control events in their own lives. Someone with an 'external' locus of control tends to be fatalistic, believing events to be determined by external forces such as chance and feeling powerless to influence those events. The person with the internal locus of control believes that events are within his/her personal control. Many researchers have felt that the concept has a place of importance in the study of compliance and non-compliance (Becker, 1985; Harrison, 1992)

The internal-external construct is very similar in structure to the health belief model in its approach to predicting decision-making. In the Rotter (1966) conceptualization of locus of control, an individual will undertake goal-directed behaviour only if he or she values the

particular reinforcers available and if he or she believes that the action(s) will lead to these reinforcers in a particular situation. For example, a person would be expected to seek information about a particular health threatening condition if the person both values the outcome (health) and believes that the behaviour will influence the outcome.

The general trend in research seems to be that non-compliance to a greater or lesser degree is associated with an external locus of control in which power is attributed to others. Kiley, Lam and Pollak (1993) found this in a study of treatment compliance following kidney transplantation. Steel, Jones, Adcock, Clancy, Bridgford-West and Austin (2000) investigated predictors of dropout from cognitive-behavior therapy for 32 patients with bulimia nervosa. Non-completers were found to have elevated levels of external locus of control.

Tillotson and Smith (1996) did research with diabetics and found that an internal locus of control predicted adherence to a weight-control regimen. Reynaert, Janne, Donkier, Buysschaert, Zdanowicz, Lejeune and Cassiers (1995)'s work with diabetic patients and metabolic control indicated that "internals" exhibited better metabolic control than "externals". He also found that the benefits of internality as regards metabolic control were not as great when this internality was extreme.

However, it has also been found that an internal locus of control was a predictor of non compliance. Barlow, Macey and Struthers (1993) found this in relation to ankylosing spondylitis patients, as did Chen, Neufeld, Feely and Skinner (1999) with home exercise programs.

5.7 Age

Developmental age and stage appears to be a significant factor in determining compliance, with certain ages and stages being more vulnerable to compliance problems. (Kimmel et.al. 1995)

5.7.1 Younger versus older patients

The general (though not inevitable) tendency appears to be that older patients have better levels of compliance than younger patients.

Magnusson, Hedges, Vanko, McCarten and Moorhead (1993), found that one of the significant factors adversely affecting follow-up compliance after emergency department evaluation, was decreasing age. Smith and Yawn (1994) studying appointment keeping in a family practice residency clinic, found similar results as did Schmaling, Afari and Blume (1998), working with asthma patients in the emergency department. Vaur et.al (1999) and Caro et. al. (1999) found that older hypertensives were more likely than younger ones to persist with treatment.

Schron, Brooks, Garkin, Kellen, Morris, Campion, Shumaker and Carum (1996) found that older age was associated with good adherence in a cardiac arrhythmia suppression trial. The same trend was found by Turner et. al. (1995) with nebulizer therapy for COPD patients and Rand et.al. (1995), working with long-term metered-dose inhaler adherence in a clinical trial.

In hemodialysis patients younger patients were found to be more likely to skip treatments than older patients (Kimmel et. al., 1995). Similarly, van Valkengoed et.al. (1999) found that older patients participated more frequently than younger patients in systematic home screening for Chlamydia trachomatis infections of asymptomatic men and women. Similar results was found in Josten, Mullett, Savik, Campbell and Vincent's (1995) study of low-income high-risk pregnant women. Younger age was associated with not keeping public health nursing appointments. Israelski, Gore-Felton, Power, Wood and Koopman (2001) found that patients diagnosed with AIDS, older in age, and receiving a higher income were more likely to keep medical appointments for HIV medication.

Costa (1996), however, found subjects at particular risk of poor compliance with antihypertensive treatment to be middle aged males, still active in work, without previous cardiovascular diseases. Similarly, a study by de Haas, Carbasius Weber, de Klerk, Bakker, Smit, Huijbers and Durans (1998) into dietary protein restriction in alkaptonuri, found that dietary compliance decreased progressively with age.

5.7.2 Childhood non-compliance

Assessing compliance in children, especially as they get older, is very complex. Initially, at least, one is assessing the parent's compliance in administering their child's medicine and parental control and management skills. Non-compliance in children is strongly influenced by the parents or guardians and evaluations of compliance in children require cogniscence of this combination (Leickly et.al. 1998).

Sunakawa et.al. (1995) studied the rational use of oral antibiotics for pediatric infections.

They found that one of the reasons for non-compliance included the child's refusal to take the drug. Leickly et.al. (1998) studied barriers to care after an emergency department visit by inner city children with asthma. Only one third of parents reported that they were able to keep the child away from known asthma triggers nearly all of the time. In caretaker compliance with different antibiotic formulations for treatment of childhood pneumonia, Ellerbeck, Khallaf, el Ansary, Moursi and Black (1995) found that overall compliance was highly correlated with the care-giver's report of difficulty in administering the medication. However, it is never clear in these instances if this is due to parental non-compliance or poor parenting skills or a mixture of both.

Becker, Drachman, Baltimore and Kirscht (1972) found mothers' adherence to medical instructions concerning their children, as typically very inadequate, especially for episodes of acute illness. Their findings offer clues to identification of potential non-compliers and suggest particular psychological attributes of the 'non-compliant' mother.

They paint an interesting and clear picture:

"A picture emerges of the mother who is relatively less likely to adhere to the medical regimen prescribed for her child. This mother is little aroused by stimuli involving health matters (often to the point of not owning a thermometer to take the child's temperature). She sees her child as relatively healthy and likely to remain so (this may be the child's first ear infection). As a consequence, she does not feel much need to attend to medical advice, to take the child to a doctor as soon as symptoms of illness appear, or to undertake special activities

to maintain her child's health. The child's present ear infection is not seen as presenting much threat, either physiologically or socially. The noncomplier is somewhat skeptical of the particular diagnosis, and of the medical care her child gets in general.

"However, the noncompliant mother evaluates her own health as relatively poor. It is difficult for her to get through the day and to care for her children, and fewer persons live in the home to help her. She is thus able to report many reasons for being unable to administer the medication properly and for not keeping follow-up appointments. In general, she is rather dissatisfied with most aspects of the clinic, and reports that she usually sees a different physician at each visit (Becker, et. al. 1972 pg. 852-853).

Another aspect is brought out by Meijer and Oppenheimer (1995) in looking at the excitation-adaptation model of pediatric chronic illness they talk about the function of the child's sick-role for the family system. This would probably be more noteworthy in conditions of family stress and/or dysfunction.

5.7.3 Adolescence

Adolescence is a difficult time to have to cope with an illness especially if it is chronic, lengthy, or requires the adolescent to make alterations in lifestyle which set him/her apart from his/her peers. Adolescents are busy with so many other life skills and projects and conflicts that this added factor is often too much for them. It forces them to be more reliant on their parents on all kinds of levels and to 'submit' to the authority of others (especially medical

others) which generally hampers their search and need for increasing autonomy, their search for identity and for their place with their peers and in society.

Brownbridge and Fielding (1994) assessed sixty children and adolescents in end-stage renal failure who were undergoing either haemodialysis or continuous ambulatory peritoneal dialysis as regards to their psychosocial adjustment and adherence to their fluid intake, diet and medication regimes. Low treatment adherence was associated with poor adjustment to diagnosis and dialysis by children and parents, self-ratings of anxiety and depression in children and parents, age, duration of dialysis, low family socioeconomic status and family structure. As adolescents are more reliant on their peer group for approval and recognition as part of their developing autonomy, chronic illness which forces prolonged dependency on parental authority figures is difficult to accept. Attempts to individuate and establish their own identities often take the form of rebellious behaviour and, in the case of chronic illness, non-compliance.

Randolph and Fraser (1998) in their work with teen asthma patients, found that chronic asthma is perceived as a burden handicapping autonomy and impairs athletic and social activity. They also found that the requirement for inhaled medications was perceived as hampering crucial peer identification.

In a similar vein, a later study Randolph and Fraser (1999) showed that adolescents were uniquely susceptible to poor outcome with asthma because of their desire for autonomy, denial of disease, preference for immediate gain rather than prophylaxis, restricted ability to control

their psychosocial and physical environment, and difficult transition to health care. They found that tobacco smoking as well as related drug abuse and passive exposure to tobacco was a major obstacle to managing adolescent asthma, together with psychosocial problems.

Simonds, Goldstein, Walker and Rawlings (1981) found that there were some significant differences in certain psychological factors between diabetic boys and girls. Girls experienced a greater degree of general anxiety and a greater degree of self-concept anxiety. Adolescent questionnaire scores on 'self-care' were significantly higher for female than for male subjects. Girls also had more frequent dysphoric feelings related to diabetes and they were more likely to regard parents, peers and siblings as treating them differently because of the diabetic condition. When upset, girls were more apt not to follow their diet. They felt that the emotional and behavioural differences between boys and girls may partially explain the differences related to blood glucose regulation. However, they point out that the obvious biological differences between boys and girls during adolescents also need to be considered (e.g. hormonal differences, body fat differences). Schlundt et.al. (1994) interviewed twenty adolescents with insulin-dependent diabetes mellitus to obtain samples of problem situations that create obstacles to dietary adherence. Obstacles to dietary adherence which were found are as follows: being tempted to stop trying; negative emotional eating; facing forbidden foods; peer interpersonal conflict; competing priorities; eating at school; social events and holidays; food cravings; snacking when home, alone, or bored; and social pressure to eat.

Murphy, Wilson, Durako, Muenz and Belzer (2001) found that adherence to HAART among HIV-infected adolescents was highly problematic. Among this sample of 161 patients

prescribed either triple drug combinations or a combination tablet and one other antiretroviral, only 41% of the sample reported adhering consistently to their medication regimen. The strongest and most consistent finding was the relationship between depression and adherence. Only 29% of the depressed subjects were fully adherent whereas 55% of non-depressed subjects were fully adherent.

5.7.4 The elderly and compliance

Although in general older patients have better compliance rates, past a certain age, the level begins to drop.

Schulz et.al. (1995) found, in a geriatric assessment, that there was evidence of intentional and unintentional non-compliance in nearly three-quarters of the patients. Elderly patients often live on near-poverty level, fixed incomes that mandate a set of priorities that often displaces the resources necessary to comply with a prescribed regimen (Anderson and Kirk, 1982).

Besides financial problems there are problems of decreasing functionality on all levels.

Masked depression and prolonged grief reactions, common in elderly patients, may result in self-neglect and non-compliance. Even in the absence of senile dementia, remote or recent memory and cognitive flexibility often are impaired in elderly patients (Anderson and Kirk, 1982). Isaac and Tamblyn (1994) in studying unintentional errors in medication compliance in the elderly found that visual perception and memory were the skills most strongly correlated with medication compliance. Nikolaus, Bach, Oster and Schlierf (1995) found that geriatric

patients had problems in reading medication instructions (not always due to illiteracy.)

Balkrishnan (1998) conducted a MEDLINE search of the English-language literature for the years 1962 to 1997 to identify articles concerning predictors of medication compliance in the elderly. Although there was some uncertainty, clear associations had been established between elderly patients' medication adherence and race, drug and dosage form, number of medications, cost of medications, insurance coverage, and physician-patient communication. However, the findings were inconsistent with regard to the effects of patients' age, sex, socioeconomic status, living arrangement, co-morbidities, number of physician visits, and knowledge, attitudes, and beliefs about health.

5.7.4.1 Handling/opening of medication containers

The apparently very simple problem of handling and opening of medicine containers is highlighted in many studies of non-compliance in the elderly. Schulz et.al. (1995) mentions that this differs with the type of the container's closure. Nikolaus et.al. (1995) measured the prevalence of difficulties in elderly inpatients in opening a range of common commercial drug packaging, in breaking a bar-scored tablet, and in reading medication instructions. Only 31% were able to perform all tasks. This was found to be so especially with older people with impaired function. Thwaites (1999) also points out that many medications are dispensed in packages or in containers which are difficult to access by older people with disabilities. Attending a medical centre, activating an inhaler, applying eye-drops or opening medication containers can prove major obstacles to medication compliance.

5.8 Sex Differences

Traditionally, males tend to be given the role in society of being strong and non-pampered. Males also tend to see their role in terms of economic viability. They therefore need to shed the sick role and its negative association, which undermines their capacity to be successful and functional.

In a study of treatment compliance following kidney transplantation, Kiley et.al. (1993) found that males were more likely to be non-compliant with medication, whereas females were more likely to be non-compliant with diet.

Cohn (2003) stated that AIDS is essentially the same disease in men and women, but a combination of social, psychological, and physiologic factors appear to define HIV disease and AIDS in women and suggest that different approaches may be needed for female patients. The likelihood that a woman will receive, adhere to, and respond to antiretroviral therapy differs from that among men. Perhaps the following can throw light on the different responses of men and women and HIV.

In an interesting study, van Dyk and van Dyk (2003) discussed the psychosocial barriers to HIV/AIDS Voluntary Counselling and Testing programmes in South Africa. In very clear terms they enumerate and discuss some of the very real doubts the people have and some of the cognitive distortions South Africa has concerning HIV/AIDS, as follows:

1. Basically people were not against the actual testing but they don't trust the confidentiality of the results.
2. Apart from the fact that because there are no treatment options for HIV in South Africa due to the policies, the people feeling that just to know their HIV status would bring depression and bring about an early death, there is the reality of rejection by loved ones and the community.
3. Or the person might not know what to do and go out and rape babies to get a cure. (Unfortunately, a very real distortion in South Africa where the virgin cleansing myth is sometimes acted on).
4. Perhaps they could go to a place where no one would know them but they needed to be close to friends and family.
5. They also mentioned the fear that the nurses would gossip and it would get out.
8. The women felt that "she (the nurse) may be nice now but when my baby is born she will refuse to treat my baby".

Furthermore van Dyk and van Dyk (2003) found that people who said they would keep their HIV positive status a secret were younger, male, living in rural areas and had lower academic qualifications. Of the married participants 13,4% said they would keep their positive status a

secret, males being more likely to do this. The participants provided the following reasoning for this (p.120-122):

"Women won't have sex with me."

"I won't tell because I won't believe I have AIDS".

"My wife won't look after me if I am sick if she knows I have AIDS".

"He will kick me out and take another woman."

"His family will say I bewitched him and take away my children if he gets it".

"He has had many girlfriends but he will blame me."

"You should always be yourself. What you do you do? To be HIV positive does not mean to be infected with AIDS (another South African distortion)

"You can still lead a good life."

"Everyone will know and treat me badly".

"I will keep on having sex until I die."

Fewer than half the participants said they would change their sex behavior if their results were negative.

"Some health workers have breached confidence and told partners and other members of the community.

"Due to the accent on antiretroviral therapy in the media people think this is the only treatment otherwise things are hopeless and treatment is expensive."

5.9 Lack of Sufficient Knowledge

Failure to comply with treatment and medication regimens have been attributed to ignorance

of disease process, course of illness and consequences of the disease. Non-compliance has been found to be related to ignorance in hormone replacement therapy (Studd et al. 1996), diabetic eye disease (Bischoff 1993), hypertensive medication (Balazovjech and Hnilica 1994; Kjellgren, Svensson, Ahlmer and Saljo , 1998), with asthma treatment (Cochrane, 1993; Gupta et.al. 1998) and with patients with primary open-angle glaucoma (Bour, Blanchard and Segal, 1993).

Similarly, lack of knowledge was found to be a factor in malaria chemoprophylaxis among travelers to India (Chatterjee, 1999) and with compliance with full immunization coverage in Nigeria (Ekunwe, Taylor, Macauley and Ayodele, 1994). In the same vein, Wagdi et.al. (1993) studied inadequate treatment compliance, patient information and drug prescription as causes for emergency hospitalization of patients with chronic heart failure. Insufficient basic knowledge about the disease (regular weighing, diet, behavior if symptoms worsen) was found in 78% of patients and complete lack of knowledge concerning the prescribed drugs in 29%. In less developed cultures these figures are probably higher.

5.9.1 Educational Level

Educational level has been found to be correlated to medical compliance in several studies (Faye et.al. 1997; Turner et.al. (1995) Lin et.al. (1995), Ko, Tsai and Chen (1995).

5.9.2 Acculturation

Pachter and Weller (1993) found that degree of acculturation was a predictor of compliance with medical therapy in mainland Puerto Ricans.

5.10 Illiteracy

Illiteracy is referred to by Kefalides (1999) as the silent barrier to health care in that it is likely to have a deleterious effect on medical compliance given that knowledge and education have a significant influence on compliance with treatment. Alexander (1999) points out that an estimated 20 to 48 million adults in the United States are functionally illiterate, and the number is reportedly increasing. He finds that many forms and brochures are written at too high a grade level for many patients to be able to read and understand them. Similarly Williams, Counselman and Caggiano (1996) found the emergency department discharge instructions to be frequently written at a level beyond the comprehension of a significant portion of the population, as did Brownson (1998) with most health educational handouts. This is probably very much more serious in developing countries, for example Gupta et.al. (1998) in suggesting a patient education programme in bronchial asthma in India, found illiteracy to be a problem. There is of course the added factor of language and ethnic barriers (Anderson and Kirk, 1982).

5.11 Inconvenience and Lack of Effort

Simple inconvenience can be a factor in failure to complete prevention or treatment of disease (Kottenhahn et. al. 1996). Cohn and Pizzi (1993) found inconvenience to be the major contributing factor in noncompliance with allergen immunotherapy. Brookoff (1994) found that inconvenience was one of the common reasons given for not filling prescriptions in pelvic inflammatory disease. Conway et. al. (1996) studied compliance with treatment in adult patients with cystic fibrosis. He found that compliance with individual treatments varied according to their perceived unpleasantness and degree of infringement on daily activities. This has also been found in patients prescribed eye-drops for glaucoma (Patel and Spaeth, 1995; Bour et. al. 1993)

Lee, Carrillo and Fleming (1997) found that some of the most frequently cited reasons for not getting vaccinated were vaccination scheduling difficulties and lack of time to get vaccinated. Kottenhahn et. al. (1996) also found this among adolescents. Wolfe (1995) studied food allergy and intolerance. He found that from a nutritional point of view the diets employed are often socially disruptive which inevitably leads to problems with compliance.

Stone, Clarke, Lovell, Steger, Hirschhorn, Boswell, Monroe, Stein, Tyree and Mayer (1998) found that HIV/AIDS patients resented the need to make medications the focus of their lives. This was obviously indicative of the deeper problem of the 'invasion' HIV/AIDS has made into their whole life pattern. Similarly, Walsh, Horne, Dalton, Burgess and Gazzard (2001), found that the majority of patients using HAART reported occasional non adherence. The

most frequent reasons for at least 'sometimes' missing a dose were eating a meal at the wrong time, oversleeping, forgetting and being in a social situation.

Lieberman, Meana and Stewart (1998) worked with cardiac rehabilitation. For Cardiac Rehabilitation Programme non-attenders, concomitant illness, transportation problems, and inconvenient timing of the program were stated to be the three most important barriers to CRP participation in both sexes. Kamiya et.al. (1995) tested 570 diabetic outpatients by written questionnaires. The principal reasons for low compliance were found to be: 'lack of time to do' and 'lack of mind to do'. 'Lack of time to do' was particularly numerous in male patients.

Carmen and Herruzo (1992), in analysing adherence to medical or psychological prescriptions, found the ability to fulfill the prescription on a practical level as well as compatibility between daily activities and the behaviors described in the prescription to be important.

5.12 Side Effects

Another important factor in non-compliance is related to the side effects of the medication or treatment which can cause people to stop it or reduce the dosage without medical guidance (Naber, 1999; Anastasio, Little, Robinson, Pettice, Leitch and Norton, 1994; Butler et.al. 1999; Bassetti, Battegay, Furrer, Rickenbach, Flepp, Kaiser, Telenti, Vernazza, Bernasconi and Sudre, 1999).

Becker (1985) points out that many persons have experienced (or heard about) the potential adverse consequences of different medications and therapies. Individuals are continually exposed by the mass media to controversies, contradictions, and often reversals with regard to public health and medical care recommendations (e.g. the recent debates about the merits and/or dangers of obtaining various influenza immunisations, sharply altering dietary patterns, and achieving an ideal body weight). Actually, a similar argument has been advanced by AIDS dissidents' view in South Africa where it has been argued that the side effects of the anti retroviral medication outweighs the benefits of such medications (Schuklenk ,2004).

Problematic side effects were found to be a deterrent in taking medicine for HIV/AIDS by a number of authors (Ickovics, Cameron, Zackin, Bassett, Chesney, Johnson and Kuritzkes (2002), Park-Wyllie, Scalera, Tseng and Rourke (2002), Harries et.al. (2001), Graney, Bunting and Russell (2003) and Andro, Bouhnik, Soletti, Bertholon, Moatti, Rossert and Spire (2001).

Bassetti et.al. (1999) in the Swiss HIV Cohort Study mention not only the actual side effects but the fear of side effects as being a deterrent to compliance. Remien, Hirky, Johnson, Weinhardt, Whittier and Minh-Le, (2003) in in-depth interviews of more than 110 HIV positive patients found that prevalent themes included ambivalence toward HIV medication and intentional non-adherence, usually to address physical side effects.

Side effects was one of the major reasons given for the discontinuation of antibiotic therapy (Brookoff, 1994; Anastasio et. al., 1994; Sunakawa et.al., 1995). Meyers, Thomson and

Weiland (1996) did a study on non-compliance in children and adolescents after renal transplantation at the Johannesburg Hospital. A total of 9% of the patients (5/56) were concerned about immunosuppressive side-effects, and indicated that this affected their compliance. Schoch, Nierhoff and Knoblauch,(1998) pointed out that clinicians should bear in mind that patients non-compliant behaviour with peak flow monitoring may have been discontinued because of adverse reactions. Loss of feeling or numbness and tingling at 2 month follow-up were significantly related to discontinuation of IFN beta-1a by 4 month follow-up in the treatment of multiple sclerosis (Mohr, Likosky, Boudewyn, Marietta, Dwyer, Van der Wende and Goodkin, 1998).

Sergl, Klages and Zentner (1998) and Johnson, Cohen, Aiosa, McGorray and Wheeler (1998)'s research indicated that acceptance of orthodontic appliances and treatment in general may be predicted by the amount of initial pain and discomfort experienced. Withdrawal bleeding is the major reason that women discontinue hormone replacement therapy (Sarrel, 1999; Keder, Rulin and Gruss, 1998). Naber (1999) indicated that the side effects of conventional antipsychotic medication, which are not necessarily restricted solely to motor symptoms, are often considered to be responsible for non-compliance. Fungladda, Honrado, Thimasarn, Kitayaporn, Karbwang, Kamolratanakul and Masngammueng (1998) studied malaria treatment in Thailand. They found that non-compliance was mostly due to adverse reactions and forgetting to take the drugs.

Even with the availability of potent and selective serotonin antagonists, chemotherapy-induced nausea and vomiting remain a major problem for many patients (Van Belle, Cocquyt,

Bleiberg, Canon, Buyse, Hulstaert, De Witte, De Keyser and Westelinck, 1995; de Boer-Dennert et. al. 1997). Besides nausea, (Reynolds, Neidig and Brashers, 1999), discomfort (Johnson et.al. 1994) and limitations of activity (Johnson et.al. 1994; de Boer-Dennert, de Wit, Schmitz, Djontono, Beurden, Stoter and Verwey, 1997) are cited as reasons for non-compliance with various treatments. Difficulty with the actual swallowing of tablets can be a negative factor in compliance (Andersen, Zwerdorff, Hjelder and Rodland, 1995), as can the taste of the medicine (al-Shammari et. al., 1995, Reynolds, Neidig and Brashers, 1999).

5.12.1 The side effects of immunization

Mulet Pons et.al. (1995) did an evaluation of the completion of influenza vaccination. They found one of the main causes of non-vaccination to be fear of the reaction. Lee, Carrillo and Fleming (1997) found that one of the most frequently cited reasons for not getting vaccinated was the fear of contracting the hepatitis B virus from the vaccination, a fear which is found with many other immunizations.

Hellerstedt, Olson, Oswald and Pirie (1999) did an evaluation of a community-based program to improve infant immunization rates in rural Minnesota. The survey data showed that, overall, enrollees in this program perceived less danger in infant immunizations than did non-enrollees, who obviously did not comply because of the apparent dangers. Chatterjee (1999) studied compliance of malaria chemoprophylaxis among travelers to India.

Discontinuation due to side effects was a common reason for non-compliance.

5.13 Dosage

Most of the literature and the research in dosage of medication and non-compliance points in the direction of fewer doses a day having greater compliance (Kiley et.al. (1993). There is however one or two points that should be noted .

The first is the factor that a missed dose on a once daily regimen has far more serious negative results than a missed dose on a three times a day regimen (Urquhart 1992).

The second is that it is far easier to remember something which is done on a daily basis. For example, among women starting HRT, those using a semi-weekly transdermal estradiol regimen have a lower rate of continuation than do those using oral estrogen daily. (Ettinger, Pressman and Bradley, 1998). However, Skaer et.al. (1993) found that patients initially prescribed antihypertensive medication requiring once-daily or once-weekly administration experienced an increased utilization of antihypertensive medication compared with those prescribed a BID (twice daily) regimen.

In general, the overwhelming opinion is that to promote compliance, fewer doses per day are more effective (Coons, Sheahan, Martin, Hendricks, Robbins and Johnson (1994). This was found in Buring, Winner, Hatton and Doerings (1999) study of *Helicobacter pylori* treatment regimens. Sclar et.al. (1994) found this in the outpatient management of infectious diseases. Kiley et.al. (1993) had similar results in a study of treatment compliance following kidney transplantation. Grob (1992) and al-Shammari et. al. (1995) and found this to be the case with

short-term antibiotic therapy. Boissel, Meillard, Perrin-Fayolle, Ducruet, Alamertery, Sassano and Benghozi (1996) found a difference in compliance between the bioequivalent BID (twice daily) and TID (three times daily) formulations of the same active agent in hypertensive patients. On another level, Henry, Rosemond and Eckert (1999) found that their older patients who were prescribed 2 home-exercises performed better than subjects who were prescribed 8 exercises.

HIV/AIDS has its own problems in this regard as dosing is complex, rigid and extensive. Harries, Nyangulu, Hargreaves, Kaluwa and Salaniponi (2001) point out that unfortunately, patients have difficulty complying with treatment which involves large numbers of pills and complicated dosing schedules.

Fogarty, Roter, Larson, Burke, Gillespie and Levy (2002), found in their literature search that more complex regimens were related to decreased adherence, but were often successfully mitigated by regimen aids.

Similar results were found by Puigvents, Riera, Delibes, Pearanda, de la Fuente and Boronat (2002) in non-compliers with HIV/AIDS medication.

5.14 Length of Therapy

As has been mentioned, length of therapy is another factor in non-compliance, and it appears that too much effort in the treatment is difficult for people. To remain healthy in certain

illnesses takes a lot of perseverance and commitment, personal commodities that are not always popular in today's society. This is an important factor for this research as cancer patients, especially those in remission, have to live through years of follow up or preventive treatment (Bradley Cathy J. and Bednarek Heather L. 2002).

In very few instances, longer duration of illness has been found to mean more compliance. An example of this is found in Garay-Sevilla et.al. (1998) study of adherence to treatment in non-insulin-dependent diabetes mellitus patients. Adherence to diet was better in patients with more years since diagnosis, perhaps because of more experience and gaining certain healthy life habits, and the eventual acceptance of living with the disease and its requirements.

Farmer, Jacobs and Phillips (1994) did a fascinating study of long-term patient compliance with prescribed regimens of calcium channel blockers. They found that the highest compliance ratio was found with treatment lengths of 2 months and then decreased with time. The deterioration of compliance over time ceased with treatment lengths exceeding 16 months, possibly as the treatment is absorbed as part of the person's lifestyle. This was also found by Menzies, Rocher and Vissandjee (1993) who worked with tuberculosis patients. Similar results were found by Royko, Denes and Razouk (1999) with compliance with orthodontic treatment, Nolting, Sanchez Carazo, De Boulle and Lambert (1998) with compliance in treatment schedules for onychomycosis and Brownbridge and Fielding (1994) in children and adolescents in end-stage renal failure who were undergoing either haemodialysis or continuous ambulatory peritoneal dialysis.

Gupta et.al. (1998) , working with asthma, found that patients disliked prolonged supervision and follow-up investigations; the factor so necessary for adequate long term compliance.

Arici, Ripamonti, Maggiolo, Rizzi, Finazzi, Pezzotti and Suter (2002) found that AIDS patients with higher CD4 counts were more likely to miss medical appointments and discontinue their follow-up, and more recently enrolled patients had a lower risk of failing to return. They do suggest, however, the possibility that the recent and more effective anti-HIV treatment played a major role in increasing adherence to follow-up.

5.15 Avoidance

Probably all non-compliance signifies some kind of avoidance though certain reasons given are related in a more direct and obvious way. Comolet, Rakotomalala and Rajaonarioa (1998) studying compliance with tuberculosis treatment in an urban environment, Tamatave, Madagascar, found that false addresses given by patients were both a methodological bias and a risk factor for future default. Halkitis Parsons Wolitski and Remien (2003) found that that avoidant coping, frequency of drinking alcohol and difficulty in communicating with sex partners about HIV were related to days of missed doses, suggesting the need or desire to escape from the reality of life with HIV as a potential explanation for poor adherence.

However, Molassiotis, Nahas-Lopez, Chung, Lam, Li and Law (2002) found the puzzling (as they say) result that higher denial/avoidance in the current study, previously associated with an increased risk of non-adherence was related with higher adherence rates.

5.15.1 Forgetfulness

Forgetfulness is a complicated barrier to compliance. Many different aspects operate here, from avoidance and denial and resistance to treatment (where there appears to be real forgetting) to the cognitive experience of actually not remembering. Researchers have found forgetfulness to be associated with non compliance. (Tebbi, 1993; al-Shammari et.al. 1995 and Mulet Pons et.al., 1995). Kessler (2003) found that patients forgot most of what had been said in the doctor's consultation. Leickly et. al. (1998) studied barriers to care after an emergency department visit by inner city children with asthma. They found that medications were forgotten some of the time. Fungladda et. al. (1998) found the same with malaria treatment in Thailand. Bour et.al. (1993) and Spaeth (1995) studied patients with primary open-angle glaucoma. According to their surveys, one of the principal causes of poor compliance was forgetfulness.

Forgetting the appointment was one of the most common reasons for non-attendance at clinic by outpatients with schizophrenia (Carrion, Swann, Kellert-Cecil and Barber, 1993). In Meyers, Thomson and Weiland's (1996) study on non-compliance in children and adolescents after renal transplantation in the Pediatric Transplant Unit at the Johannesburg Hospital, they found that the noncompliant group of patients more often missed clinic visits, forgot to take their medications, took more medications and remembered fewer of their names than the compliant group. Fong, Ho, Fung, Lee, Tse, Yuen, Sin and Wong (2003) found that though most of their HIV/AIDS patients were monitored and maintained a good adherence level

despite using a complex HAART regimen, partial drug adherence was, associated with the psychosocial factors of missing clinic appointments forgetfulness and a busy work life.

Conway et.al. (1996) found that the most common reason given for omitting treatment in adult patients with cystic fibrosis was forgetfulness. This is similar to what Balazovjech and Hnilica (1993) found in their study of irregular drug taking in hypertensive patients.

5.16 Support Systems

Support systems, especially that of the immediate family are fairly crucial for the person to take care of themselves and their illness. Hanson, De Guire, Schinkel and Kolterman (1995) found that positive family relations (high family cohesion and low family conflict), especially during the first years of illness, related indirectly to good metabolic control through positive adherence behaviors. High levels of family-life stress related to worse metabolic control directly, and also indirectly via poor family relations, which in turn related to poor adherence to treatment.

Wong (1995) studied compliance with tuberculosis treatment in Hualien aborigines. He found that single patients (unmarried, divorced, widowed), those with a low tuberculosis recognition score, and alcohol consumers had a higher chance of non-compliance and hence lower chance of completing treatment.

Cox (2002) found that having emotional support was a factor predictive of a "good complier"

with HIV medication. Schron et. al., (1996) studied adherence in a cardiac arrhythmia suppression trial. One important factor for predicting adherence was the presence of a spouse. Christensen (1995), in studying the characteristics of attenders and non-attenders at health examinations for ischaemic heart disease in general practice found that the attendance was significantly higher for cohabitants than for single men. Kulik and Mahler (1993) worked with adjustment and compliance after coronary artery bypass surgery. They found that higher support was significantly and independently predictive of better emotional status (lower anxiety, depression), perceived quality of life and compliance with recommended behaviors (ambulating and not smoking).

Garay-Sevilla, Nava, Malacara, Huerta, Diaz de Leon, Mena and Fajardo (1995) concluded that adherence to treatment in non-insulin dependent diabetes mellitus patients was associated with social support. Pham et.al. (1996) looked at the role of the Health Belief Model in amputees' self-evaluation of adherence to diabetes self-care behaviors. The correlative analysis revealed significant relationships between perceived social support and adherence to diet, and between perceived social support, barriers and adherence to the practice of exercise. Sugarman, Bauer, Barber, Hayes and Hughes (1993) studied the factors associated with failure to complete treatment for diabetic retinopathy among Navajo Indians. Factors associated with incomplete treatment were absence of a household vehicle, female sex and marital status other than currently married.

Davis, Tucker and Fennell (1996) found that in the pediatric patients with renal failure they studied there were significant correlations between some of their adaptive functioning skills

and measures of their medication adherence, diet adherence, and clinic appointment adherence; for the patients also, some measures of their family behavior were significantly correlated with measures of their medication adherence and diet adherence. In their study of treatment compliance, following kidney transplantation, compliance and non-compliance were, among other things, associated with the perceived amount of social and family support (Kiley et. al., 1993).

Interesting results were found by Foulkes, Boggs, Fennell and Skibinski (1993). They studied social support, family variables, and compliance in renal transplant children. Results indicated that children whose fathers gave more emotional support or were more informative were less compliant with azathioprine and cyclosporine. Children from families experiencing numerous stresses were also found to be less compliant with azathioprine. Finally, compared with older children, younger children were found to be less compliant with cyclosporine.

Sometimes even family support was not sufficient as the family felt they were not equipped to give that support. Thomas (1994) did a study of the response to protein-modified diets for propionic acidemia in twelve patients. He found the main difficulty causing non-compliance to be the parents' inability to take care of the patient due to other family responsibilities. The parents were unable to cope with the demands of the diet and medications.

5.17 Socioeconomic Status

The cost of treatment and medications has been found to be a major factor in non-compliance.

(Adwok, 1994; Sternberg, 1998 ; Richardson, Simons-Morton and Annegers, 1994; Howard, Clarke, Elia, Hutcheon, Kaye and Windsor, 1995; Smith, Thompson, Woodruff and Hiscox, 1995; Samson and Showalter, 1996, Jonna, Delfino, Newman, Tope and Jones, 1998,; Butler et.al. 1999). Especially in countries where treatment is not free, cost is a formidable barrier to persistence or perusal of therapy. This is also the case where an impoverished patient cannot afford even the transport fees. The absence of medical insurance is also a big factor in non-adherence. (Magnusson et.al. ,1993 and Nordberg, Barlow, Chalew and McCarter, 1993).

Difficulty in meeting the cost of medications was one of the reasons given for non-compliance in hypertension (Butler et. al. 1999), heart failure disease management (Rich, 1999)and the wearing of stockings for the prevention of recurrent venous ulcers (Samson and Showalter, 1996). Johansson, Diwan, Huong and Ahlberg (1996) did an exploratory study in a district in Vietnam on staff and patient attitudes to tuberculosis and compliance with treatment. The patient's economic situation was found to be an important determinant of compliance and non-compliance.

Richardson et. al. (1993) and Gupta et.al. (1998) in suggesting a patient education programme in bronchial asthma in India outlines many barriers to compliance high cost of inhalers, poverty and inadequate contingency fund for prolonged treatment in most families.

Kiefe and Harrison (1993) concluded that health-care-delivery related factors such as no copayment requirements were strongly associated with appointment-keeping in a public hospital population. Febrile children evaluated in a medical system with prearranged

follow-up appointments and free medical care are more likely to comply with recommended follow-up than are those evaluated in a system where payment and appointments are the responsibility of the parents (Hemphill, Santen, Howell and Altieri, 1998).

This factor is particularly problematic in Africa. Needham, Godfrey-Faussett and Foster (1998) studied barriers to tuberculosis control in urban Zambia. They point out that the economic burden of tuberculosis on patients creates barriers to prompt diagnosis which may lead to continuing transmission of the infection. They found that important economic barriers included transportation expenditure, cost of 'special food', and lost income. Osei and Commey (1994) studied drug compliance among parents and guardians of children in Accra, Ghana. They found poor economic standing to be an important factor. Nordberg, Holmberg and Kiugu (1996) explored the interface between first and second level of care (from clinic to hospital): referrals in rural Africa. They found that the rates of formal clinic-to-hospital referral were very low. The reasons given for this included patient inability to pay user fees, transport outlays (as well as access to transport), and other expenses.

5.17.1 Transport

Lack of transport, especially in the more undeveloped countries can be a major factor in non-compliance. (Carrion et.al., 1993; Nordberg, Holmberg and Kiugu, 1996; Halm et.al. 1999) Nordberg et.al. (1996) found that transportation difficulties were one of the most common reasons for non-attendance at outpatient clinics. In the studies by Sugarman et.al. (1993) and Ide et.al. (1993), transport was also found to be a problem. Lieberman et.al. (1998) and Halm

et.al. (1999) found that for cardiac rehabilitation non-attenders, transportation problems were important barriers to participation.

5.18 Fear of Social Stigma

The culture and social group of the patient has a great deal of influence. There is also the factor that certain illnesses are associated with a stigma which almost gives the patient a new, negative identity. This has been especially relevant with regards to Aids and HIV where part of the spread of the illness is brought about because people cannot bring themselves to 'confess' their illness because of a very real fear of rejection and abandonment (van Dyk and van Dyk, 2003). This stigma in AIDS and other illnesses can undermine compliance, medical behavior and general attitude to health. Especially in South Africa, the stigma of AIDS brings about an avoidance of treatment and an avoidance initially of establishing a diagnosis. There are also many cultural beliefs which have come to influence the perception of the illness such as the curse of ancestors or of the white man or even a conspiracy theory. By keeping HIV and AIDS a secret often means a continuous spreading of the condition , as pointed out by van Dyk and van Dyk (2003) who discussed the psychosocial barriers to HIV/AIDS Voluntary Counselling and Testing programmes in South Africa enumerating some of the doubts and cognitive distortions South Africa has concerning HIV/AIDS. Some of the doubts centered on the fear that confidentiality would be breached or that they would be stigmatized by the medical profession. Most of the fears and doubts concerned fear of rejection on all levels especially when they really became ill, then their family might reject them.

Rubel and Garro (1992) point out that the twin problems of delay in seeking treatment and abandonment of a prescribed regimen derive, often, from the health culture of the patients. That is, the understanding and information people have from family, friends, and neighbors as to the nature of a health problem, its cause, and its implications. They also mention people's confusion as to the implications of the tuberculosis symptoms, and the social stigma that attaches to tuberculosis.

Johansson et. al., (1996) did an exploratory study in a district in Vietnam on staff and patient attitudes to tuberculosis and compliance with treatment. The study revealed some important aspects of staff and patients' attitudes to tuberculosis and its treatment. There, tuberculosis is considered a 'dirty' disease, which mainly affects poor people. There is a tendency to avoid telling others about it. Obvious symptoms are explained as 'being overworked'. A patient with tuberculosis feels 'less respected' by others. The social stigmatization leads to delays in seeking medical care.

Gupta et.al. (1998) mentions the problem of social stigma in asthma which could stop a person going for treatment because of the fear of being labeled and therefore avoided. On another level, there is non-compliance with the wearing of orthodontic appliances as the children fear ridicule from their classmates.

5.19 Lack of Medical Facilities

Sometimes, especially in developing countries, there are very real problems of compliance

based not on the patients' lack of trying, but by the factor of limited medical facilities. For instance, Rubel and Garro (1992) in studying non-compliance in tuberculosis found that organizational problems in providing adequate follow-up services were a factor.

Gupta et.al. (1998) in India, found poor medical infrastructure, inadequate health care facilities, overcrowding in all hospitals, insufficient para-medical staff forming a pattern of non-compliance. Nordberg, Holmberg and Kiugu (1996), in rural Africa, found that the rates of formal clinic-to-hospital (1st. to 2nd. level) referral were very low. One of the reasons for this was lack of feedback information from hospital to clinic. Osei and Commey (1994) found the non-availability of drugs at the hospital pharmacy in Ghana to be a problem with compliance.

5.20 Post Traumatic Stress

Two significant and meaningful studies have looked at post traumatic stress as a significant factor in non-compliance. Shemesh, Rudnik, Kaluski, Milovanov, Salah, Alon, Dinur, Blatt, Metzkor, Golik, Verd, Cotter (2001) found significant results in their study on posttraumatic stress symptoms and non adherence in survivors of myocardial infarction. Another team led by Shemesh (Shemesh, Lurie, Stuber, Emre, Patel. Vohra, Aromando and Shneider, 2000) had found that clinically significant nonadherence was associated with the full spectrum of Post Traumatic Stress Disorder (PTSD) symptoms in his sample of pediatric liver transplant recipients. "It was especially associated with a high avoidance score, which suggests that avoidance of reminders of the disease (e.g. medications) may be a mechanism of

nonadherence" (Shemesh et.al.,2000, p. 1)

The diagnostic criteria for PTSD in the DSMIII-R (American Psychiatric Association, 1987) specifically excluded patients with medical illnesses such as cancer and Acquired Immune Deficiency Syndrome from the diagnosis of PTSD. The diagnostic criteria for PTSD in the DSM-IV (American Psychiatric Association, 1994), however, reflects a shift in emphasis from the event itself to the psychological experience of the person who takes part in the event (e.g., being diagnosed with or surviving cancer). Therefore people with histories of cancer (and other illnesses) can now be considered to be at risk for PTSD. (Cancer Information Home Page). There is now room to say that physical illness, especially where it is life threatening (or feels life threatening to the patient) can be as traumatic to the individual as, for instance, being hi-jacked, or held up at gun point. The avoidance part of PTSD would operate very forcibly in preventing a patient from availing themselves of the fullest benefits of their medical treatment.

5.21 Summary

Throughout the literature and research on medical non-compliance, certain factors emerge as predictors and reasons for non-compliance. These range from the very practical factors such as dosage, doctor's instructions not being followed because the patient did not understand or forgot what the doctor said or could not read written instructions, transport and side effects, to the more complex factors such as the doctor-patient relationship, the presence of psychopathology or the complex dynamics of 'inconvenience'.

Only in the last two years a new factor has emerged as a reason for non-compliance , that of Medical Post Traumatic Stress.