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Treatment adherence among primary care patients in a historically disadvantaged community in the Western Cape: A qualitative study.

by

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DECLARATION

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ABSTRACT

The question of treatment adherence remains a concern that affects the health outcomes of patients attending public health clinics in South Africa. Patients with chronic illnesses who reside in impoverished communities face particular challenges in terms of managing the often complex aspects of their treatment. The sample for the study was selected from patients diagnosed with diabetes or hypertension attending public health clinics in the Boland area of the Western Cape. A total of 23 patients between the ages of 32 and 80 participated in the study. All participants were Afrikaans-speaking had been classified as Black or "Coloured" under the apartheid system and as such were all historically disadvantaged.

Participants were selected by means of convenience sampling and were asked to participate in qualitative interviews under confidential conditions. The interviews addressed various aspects of the participants' experience of their illness and treatment and were conducted by two trained interviewers. Interviews were recorded, transcribed, and entered into Atlas.ti, a computer programme that assists in the analysis of textual data. The analysis of the data focused on the content of participants' concerns and difficulties associated with adhering to treatment recommendations.

The themes that emerged from the study included participants' attribution of the origin of their illness, their experience of their illness and of the health care system, their own concerns about the consequences of poor adherence, financial and problems, psychosocial support, spirituality, alternative medicine, and patients' own understanding of the symptoms of poor adherence.

The results of the study are discussed in terms of the often hierarchical relationship between health care workers and patients. Public health care workers often hold sceptical and suspicious views about their patients regarding their illness, symptoms, and level of adherence. As such, patients may be regarded in a paternalistic manner and in some cases even be admonished by health care workers for poor adherence. Yet, competing social realities often inhibit patient adherence. These include financial constraints, being labelled a patient, side effects of medication and family opposition to treatment. Adherence may also be related to the notion of responsibility for the causes of and solutions to medical problems. The

results of the study were considered in terms of four models of attribution of responsibility for the origin of and solution to the medical problem as identified by Brickman, Rabinovits, Karuza, Coates, Cohn, and Kidder (1982). These models are the moral model, the compensatory model, the medical model, and the enlightenment model. The medical model is the most dominant in the South African public health system. Yet, in many instances, participants appeared to adopt other models of engaging with the causes and solutions to their illness conditions.

The question of participants' understanding of the consequences of adherence is discussed in terms of the theoretical work by Pepper's (1942), who proposed four possible perspectives with which people may view the world. These worldviews are formism, mechanism, contextualism, and organicism. In many instances adherence as a means of controlling somatic symptoms occurs as part of a logical and mechanistic understanding of health. However, in terms of an organismic worldview, adherence may represent an effort to restore equilibrium to the patient's constitution that has spiralled into disequilibrium as a result of disease.

The significance and future direction of this line of research includes the development of a reliable and valid psychometric instrument to validate the data yielded by the study and to design a psychosocial intervention aimed at enhancing optimal adherence. The intended result of such efforts is to maximise the effectiveness of health interventions and thus contribute to patients' well-being and quality of life.

CHAPTER ONE

INTRODUCTION AND STATEMENT OF THE PROBLEM

Aim of the study

The question of ensuring treatment adherence is among the many challenges associated with providing quality patient care within the South African public health system. Patient non-adherence invariably has a negative effect on health and quality of life (Dick, Schoeman, Mohamed, & Lombard, 1996). Yet, the barriers to adherence among historically disadvantaged rural patient populations are poorly understood. The present study examines the problem of patient non-adherence in rural and semi-rural predominantly "Coloured" and African communities in the Boland area of the Western Cape. The primary aim of the study is to provide a culturally and contextually relevant understanding of the factors that patients diagnosed with Type II diabetes and hypertension attending primary care clinics perceive as barriers to treatment adherence.

Background and significance

Patient non-adherence is both costly and deleterious to health. Treatment regimens for conditions such as hypertension and Type II diabetes usually require strict adherence to instructions (Pladevall, 2004; Steinman, 2004). Medications that are prescribed following consultation with a medical professional are usually dispensed with an expectation of close to perfect adherence. Such expectations pertain to the dosage, timing, ingestion with specific foods, contra-indications regarding ingestion with other medicines, and consistent adherence to the treatment regimen over time (World Health Organisation 2003). These details are of crucial importance in maximising the health benefits from medical treatment. Patient non-adherence may therefore have severe implications for the control of symptoms, recovery time, quality of life, and mortality (Zgibor et al 2004). Treatment complications may also result from non-adherence. For example, when a given dosage is determined to have little or no effect a medical professional may prescribe a dose increase with the assumption that the original dose was insufficient. Yet, non-adherence may account for a poor treatment outcome and in these circumstances overdosing may constitute a serious health hazard (Preston, 2004). In terms of financial implications there is likely to be considerable wastage when resources are directed at medical consultations, purchase of medication, transport to appointments and other aspects surrounding medical care while adherence to treatment remains low (World Health Organisation 2003). For these reasons it appears that in many medical settings, particularly public health facilities, the question of adherence is of considerable importance in order to enhance the effectiveness of treatments and thereby maximise health outcomes.

Little research into treatment adherence has been conducted in rural and semi-rural community clinics in South Africa. Indeed, public health in rural areas has received less attention from authorities in comparison with urban and peri-urban areas. As such there is only a small number of publications in peer reviewed accredited journals that address treatment adherence in rural South African communities. The absence of a knowledge base concerning treatment adherence among rural primary care patients in historically disadvantaged communities in South Africa suggests that a primary research need is to identify the factors associated with non-adherence from the perspective of patients. It therefore appears that the question of adherence is an under-researched area in the public health arena in general and in the context of treatment for chronic illnesses in particular.

CHAPTER TWO

REVIEW OF THE LITERATURE

Various factors have been identified in the literature as having importance influences on adherence. These most commonly include social and economic factors and psychological factors. Adherence in turn plays an important role in determining quality of life, in either positive or negative ways. Thus social and behavioural factors ultimately exert important influences on health, health care utilisation, and benefit to patients.

Social and economic factors

Social and economic factors often combine to yield poor adherence outcomes. Among an indigent sample Simoni (1995) found low levels of adherence to the correct number of pills, dosing schedules, and special instructions. Poverty in itself is likely to affect adherence as financial resources may need to be directed elsewhere, funds for travel to the doctor's office may not be available, and child-care may not be readily accessible. The competing demands of several responsibilities such as work and family life, along with and the stresses associated with poverty and difficult life circumstances, obviate an acknowledgement of the importance of complying with treatment regimens (Simoni, 1995). These competing demands may be especially important threats to adherence among the rural poor.

Health literacy

Health literacy is likely to constitute a barrier to adherence (Sullivan, Dukes, Harris, Dittus, 1995). Health literacy implies an awareness of the importance of adherence despite the absence of actual symptoms (Turk, Salovey, & Litt, 1986). Many patients only consider medication as tertiary measures following the onset of symptoms, rather than as prophylactic interventions. Behavioural regimens such as low salt, fat and sugar intake, exercise, and adherence to specific medications in many cases serve a preventive function. When adopted for such purposes as reducing hypertension or maintaining appropriate insulin levels in the case of diabetics, adherence for many patients may appear to be unimportant. Yet, the longer-term health consequences of non-adherence may be severe, as symptoms will inevitably develop. Health literacy is often related to educational level. Among poor communities in South Africa characterised by poor educational opportunities, health literacy is likely to be low, accounting in part for low levels of adherence.

Psychological factors

Social support: Considerable research has demonstrated consistently that social support is a strong predictor of medical adherence (e.g. Simoni, et al. 2002; Safren & Otto, 2001; Bearman & La Greca, 2002; Williams & Bond, 2002; Rhodes, Martin, & Taunton, 2002). Social support for adherence is defined as encouragement from family and friends for the patient to co-operate with the recommendations and prescriptions of a health professional (DiMatteo 2004). The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation. An issue related to social support, namely, the relationship between the doctor and patient, has also been shown to be strongly associated with adherence (Roberts, 2002; Ciechanowski, Katon, Russo, Walker, 2001; Catz, Sheryl, Heckman, Kochman, & DiMarco, 2001). Data obtained by Roberts (2000) further suggested that medical providers viewed communicating with patients about adherence issues as an essential component of the health care service. While the provider-patient relationship may ostensibly constitute an example of social support, it also extends beyond this. The health worker is often seen as a person of authority, in the possession of specific expertise that is unobtainable elsewhere, and as someone in whom the patient solely invests hope for assistance in the recovery process (Bury 2004).

Self-efficacy: Patients who have a greater level of confidence in being able to carry out a doctor's instructions are likely to engage in such activities to a greater extent than those who do not. Thus self-efficacy has also been associated with improved levels of adherence (Molassiotis et al. 2002; Miller, Ogletree, Walshimer, 2002; Williams & Bond, 2002). Yet, several factors interact to affect self-efficacy. Chief among these are patients' the level of comfort with interacting with the health care system, their relationship with medical personnel (Roberts, 2002) and the complexity of the treatment regimen (Kubeck, 2002). Together with limited health literacy, the competing demands of daily living and inadequate financial resources impact on adherence self-efficacy in a manner that may be unique to primary care patients residing in historically disadvantaged South African communities.

Mood disturbance: Many studies have documented the role of psychological distress as affecting adherence either directly or indirectly (e.g. Sternhel & Corr, 2002). Depression in particular has been documented to have a strong association with medical non-adherence (Coleman, 2002, Sternhell & Corr, 2002). Persons exhibiting symptoms of psychological distress or depression are not likely to assert themselves in remaining adherent to medication regimens that in some cases require the ability to follow complex instructions from a medical professional (Park, Hong, Lee, Ha, & Sung 2004). The cognitive disturbances that occur as part of the depressive symptom picture may inhibit the patient's ability to concentrate and to remember important details such as the recommended time of day or sequence of administration (Wang et al 2002). In cases in which patients are medicated for more than one illness, the treatment regimen may be particularly complex and require intact cognitive abilities, high levels of motivation to follow instructions, and a sense of hopefulness about the future.

Quality of life: An important factor associated with adherence is the extent to which the patient's quality of life is compromised by the treatment regimen. Thus factors such as drug toxicity or intolerance (Park, Scalera, Tseng, & Rourke, 2002), discomfort associated with side effects, (Schuman & Omit, 2001), dissatisfaction at having to make changes in terms of diet (Lynch, Repka, Nagel, Birk, Gohara, Leighton et al., 2000), exercise activities (Izquierdo, Powell, Reiner, & Fontaine, 2002), work habits (Rodham & Bell, 2002) play an important role in patients' quality of life. In some cases diagnosis may have occurred at a pre-symptomatic level and medication or behavioural changes prescribed. Under these circumstances there are few directly perceived benefits associated with adherence. Combined with poor quality of life brought on by medication side effects, the absence of a perceived benefit of taking medication or engaging in specific health behaviours may be further barriers to adherence (Cote, Farris, Feeny, 2003).

<u>The assessment of treatment adherence:</u>

Accurate assessment of treatment adherence, particularly in the form of self-report measures, is often compromised by inaccurate estimates obtained from patients. Health professionals too may also fail to adequately estimate the extent of patient cooperation with treatment (Gross, Bilker, Friedman, 2002). Most doctor-patient encounters are limited to a consultation time of only a few minutes, thus not permitting extensive inquiries into patient adherence. Other methods of assessment such as inspection of hospital, clinic, and pharmacy records may yield some objective data about whether or not prescriptions have been filled. However, not only are such records sometimes inaccurate reflections of actual prescriptions (Van Svellen, Johiro, Tichacek, 2002), they also do not accurately predict whether the medication has been taken by patients as prescribed. Moreover, the behavioural dimensions of treatment regimens such as diet, exercise, sleep, recreation, and relaxation are not reflected in such records. Hypertensive patients, for example, are required to reduce their salt intake so as to bring about a change in blood pressure, which in turn decreases vulnerability to myocardial infarction or stroke. Accurate measurement of adherence to these prescriptions is often extremely difficult, as patients for various reasons overestimate the extent of their cooperation with their doctors. These measurement difficulties suggest that researchers who conduct studies of adherence may be obliged to accept more error in adherence data than when measuring other variables.

Summary

The issue of treatment adherence is a complex medical and behavioural phenomenon. In impoverished South African communities anecdotal evidence suggests that adherence to medical treatment regimens is a widespread problem. In the context of meagre financial resources, inadequate public funds directed at health care, and a low proportion of medical personnel to patients in need of care, the question of treatment adherence is likely have far-reaching health, economic, and social implications. The present research is located in the context of post-apartheid South Africa, in which rapid changes continue to occur in the delivery of health care, the uptake of services, and the locus of responsibility for ensuring optimal community health.

CHAPTER THREE

RESEARCH DESIGN AND METHOD

Research Setting

The present study was conducted at clinics within the Stellenbosch Municipality in the Western Cape province of South Africa. The Stellenbosch Municipality is located approximately 50km east of Cape Town and has a total population of 103,756 of which 16,297 were African, 58,107 were "Coloured", 26,999 were White, 284 were Indian, and 2,069 were categorised at "Other" (Local Government in South Africa, 2002-2004). Employment by the main industries is as follows: Farming: 9551; Manufacturing: 6,358; Utilities: 184; Construction 2,341; Trade 4,689; Transport 977; Business Services 2,677; Social Services: 7,199 (Local Government in South Africa, 2002-2004). There are wide socio-economic disparities within the Stellenbosch Municipality and levels of poverty and unemployment are high. In terms of transport, taxi services account for approximately 90% of the road-based public transport market. According to official statistics 80% of the population in the municipality has access to health facilities (Local Government in South Africa, 2002-2004). The commercial nature of agriculture in the Stellenbosch Municipality, especially as this pertains to the wine industry, has created economic conditions that make the area qualitatively different from other South African rural areas. Most noticeable is the wide disparity of wealth among residents of the area.

Participants

The population from which the sample for the present study was selected consisted of patients diagnosed with Type II diabetes or hypertension attending primary health care clinics in the Boland area (Aan-het-Pad, Klapmuts, Don and Pat Bilton, Victoria Street, Kayamandi, Kylemore, and Idas Valley Clinics). Participants were invited to participate in a research study entitled *Treatment Adherence in Primary Health Care*. The eligibility criteria for participation were a formal diagnosis from a medical doctor and a prescription for medication and/ or behavioural adaptations aimed at symptom reduction or control. The exclusion criterion was diagnosis with a psychotic disorder. Convenience sampling was used to enrol participants into the study and sampling was conducted to redundancy. Thus when themes began to recur in interviews, the sampling process was considered to be complete. A total of 23 patients between the ages of 32 and 80 participated in the study. All participants were Afrikaans-speaking and had been historically disadvantaged under the apartheid system. No one who was approached declined to participate.

Procedure

A research assistant approached each patient in the clinic waiting rooms and informed them of the opportunity to participate in the study. Patients who agreed to participate were escorted to a private room within the clinic where they were explained the details of the study and asked to sign an informed consent form. A financial incentive was not offered in return for participation. However, participants were informed of the opportunity to know the results of the study when these were available. They were also informed that recommendations based on the study would be shared with clinic staff in order to improve the health care service. In addition they were assured that they would never be identified by name and that the data they provided would not be linked to them personally in either the information sessions or in any publications that resulted from the research.

The interview process

Upon agreement to enrol in the study, patients were asked to participate in individual interviews. The interviews were conducted in Afrikaans, as this was the first language of most people residing in the Boland area. At the beginning of the interview participants were assured of the confidentiality of their responses. They were informed that all data (audiotapes, notes, and interview transcripts) would be kept in locked cabinets at Stellenbosch University and would be accessible only to members of the research team. The interviewers were two white women (one in her mid-twenties and one in her forties) who had received training in conducting qualitative research interviews.

The interviews were semi-structured and guided by the interviewer in order to elicit from each respondent a comprehensive and detailed narrative that could be analysed qualitatively (Lofland & Lofland, 1995). The interviewer asked open-ended questions to learn participants' understandings of the way in which they thought of their illness, the treatment they were receiving, their relationship with the health care system, and the challenges they experienced in adhering to their treatment. These questions served as a catalyst to further discussions guided by the interviewer. Respondents were asked to engage in an exploration of their responses with the intention of eliciting specific descriptions of their experience and the challenges they experienced regarding treatment adherence. A list of initial questions used in the interviews is presented in Appendix I.

Analysis

Interviews were recorded, transcribed, and entered into Atlas.ti., a computer programme that assists in the analysis of textual data by enabling an investigator to manage large amounts of text with the use of linking and search functions. Atlas.ti thus facilitates textual analysis and interpretation, by means of various coding procedures described below. The analysis of the data focused on the content of the participants' salient concerns and difficulties associated with adhering to treatment recommendations.

The analytic outline was revised based on each additional piece of data input, with the process of open coding, axial coding, and selective coding (Strauss & Corbin, 1998) forming the basis for the grounded theory analytic process. Open coding consists of identifying codes or themes in the original transcripts. Axial coding involves arranging the basic codes into inclusive categories. Selective coding is the process of identifying overarching core categories at greater levels of abstraction in order to form a conceptual model that is the grounded theory. Finally, Atlas.ti was used to call up all the linked data with each category for final examination to be certain that the grounded theory model indeed accurately represented the data. The above process resulted in the identification of a composite list of overarching themes that represent the concerns, issues and problems that respondents associated with adherence to their treatment recommendations.

CHAPTER FOUR

RESULTS

Overall, the sample responded positively to the request to participate in the study and no one who was approached declined to participate in the study. Most participants were eager to tell their stories and were responsive to cues and prompts from the interviewers. The narratives that emerged were of three discernable types. These were: descriptions of the experience of the illness; concerns related to adherence; psychosocial issues related to illness and adherence.

Attribution of the origin of the illness

Respondents held a variety of perspectives regarding the cause of their medical condition. More than one respondent suggested that hypertension might be related to pregnancy and childbirth. Elsie, a 45 year old woman stated:

> *It's in the family. I first had low blood pressure but after the two babies I had I heard that my blood pressure was high*

Similarly, Johanna, a mother of three stated:

> *The high blood is probably from when I was pregnant and they realised that I have sugar. And after the pregnancy the sugar stayed behind and the high blood did not go away either.*

Pregnancy induced hypertension or toxemia is relatively rare, especially in mothers who have had uncomplicated pregnancies. Yet, some women have been shown to be at elevated risk for this condition (Robert, 1993). Dorie, a mother of two made a similar attribution regarding the origin of her diabetes, stating that:

> *I did not think I would get sugar. Because with the babies... my first baby who is now going to be ten... I had sugar (after he was born) and it went away and after the baby who is now four, I had sugar again and it also went away until last year. I never thought I would be a diabetic.*

While indeed, any woman may develop gestational diabetes, specific risk factors include obesity, a family history of diabetes, and having previously given birth to a very large infant (Alberico, et al, 2004). One respondent, Anna, made the connection between hypertension and psychological factors, specifically anger by noting:

> *High blood exists if you get angry with someone, right? Or if you get a pain in your head.*

Finally, Lauretta a 55 year old woman, attributed her condition to heredity:

> *I actually never asked how a person gets high blood. I always thought that high blood is an inherited sickness. It is, isn't it?*

The various attributions that respondents disclosed regarding the origin of their illness conditions, namely pregnancy, anger, and heredity, are likely to play a role in the manner in which they are conceptualised. Such illness conceptualisation are in turn likely to affect the way that adherence is thought about and implemented.

Experience of the illness

In their narration, respondents gave considerable attention to their experience of their illness. Most participants narrated in a sequential manner their experiences regarding the onset of symptoms, their response to their diagnosis, their experience in treatment, and adaptation to living with a chronic illness. The typical narrative usually involved a detailed description of the participants' initial experience of the illness, leading him or her to seek medical attention. The following statement by Floris, a 52 year-old woman, indicates acceptance of her health status following her diagnosis with diabetes:

> *I simply had to accept it. It is like that and that's how it must be. There is nothing I can do about it. I guess it just has to be that way.*

The above quotation suggests that the participant does not necessarily see the need to question the diagnosis or the extent to which it will affect her life, as the medical provider's pronouncement is considered to be final on matters concerning health.

Lydia, a 60 year, old woman considered the possibility that the physical symptoms she experiences is related to her hypertension by stating:

> *When I feel pressure on my head and I am in the sun a lot, then I feel... I don't know...I wonder if it is the high blood that makes me feel like this.*

Thus the physical discomfort and pain she describes is attributed to her condition of hypertension. The same respondent was unclear about the source of her illness and considered the possibility that medication for arthritis may be related to her disease:

> *Now I don't know. Now the woman that I work with says to me that I should not take the arthritis pills because this might be why I get high blood.*

Experiences with the public health care system

Most respondents indicated some level of concern about the question of adherence to treatment recommendations. Various inter-personal relationships, such as relationships with clinic staff, who are the main interface between patients and the health care system, shaped the way in which respondents thought of the question of treatment adherence. Bettie, a 61 year old woman stated:

> *At some point I did not take my medication at all and I also did not go to the clinic to collect it. And then when I went back, the sister told me that if I did not come and collect it again, and if I had a problem again, then I would not be able to come to them again.*

The concern expressed in the above quotation suggests a conditional and somewhat authoritarian relationship with the clinic staff and therefore with the health care system. Administrators in public health clinics have been compelled to institute regulations regarding attendance. The respondent thus indicated an awareness of the conditions associated with receiving treatment from the clinic and appeared to acknowledge a bureaucratic and officious tone in her relationship with her service providers.

In addition to engaging with the health care system as a bureaucratic entity, some respondents also expressed concern that the service they received was mechanical rather than empathic and caring. Lena, a 51 year old woman stated:

> *It does not help that when you go and visit the doctor and they don't examine you. They only write out a prescription. You can't just take medication. They first have to find out what the problem is.*

The above quotation appears to express a need to be listened to and heard, rather than to simply have a course of action identified. When the health care system is thought of as a bureaucracy, whose task is to process people, the subjective experience may be alienating. Such a sense of alienation has the potential to create divisions between providers and patients rather than placing all role-players, including the patients on the same treatment team. Relationships with individual health care personnel may also be salient for some people. Stella, a patient with diabetes remarked:

> *That Friday afternoon I was sick and that's why I went back to the clinic. So she (the nurse) scolded me because I came on that specific day. She said that if I had not been sick I would not have come to the clinic.*

Similarly, Dottie, a patient with hypertension stated:

> *For a while I felt OK and I thought I didn't need anything. But after last Monday I felt that I had to come back (to the clinic) and so the sister scolded me. My blood pressure was already high because, look, it's my fault.*

The theme of being "scolded" for non-adherent behaviour appears to pervade many of the interviews. The fact that a nurse appears to have the right to admonish the patients for not attending the clinic most likely has its roots in the authoritarian relationship between health care staff and patients that has historically been characteristic of public health practice in South Africa. Elsie, a patient with hypertension, provides a further example of the authoritarian and patriarchal character of the provider-patient relationship by remarking:

> *If you don't take your pills then you are naughty. Because you have to take it. If you don't then you are naughty.*

The idea that mature adults are referred to as "naughty" suggests that they may be viewed as children by their nurses, whose role it is to discipline them and to correct errant behaviour. Not taking one's pills in the manner prescribed is seen as errant in the context of the public health system where nurses engage with large numbers of patients under conditions of limited time and resources and considerable stress. Thus it is not surprising that the nurse-patient relationship and therefore the relationship between the patient and the health care system is characterised by patriarchy rather than egalitarianism.On the other hand, the specific aspects of the way patients are managed at clinics were also a matter of concern. For example, Dorie, a 50 year old woman appeared disconcerted with the long time she needed to spend waiting to get her prescription filled. She stated:

> *We are here (at the clinic) today and now there is no more medication. We have to return tomorrow and sit and wait again to get more medication.*

Another patient, Magdalena, stated:

> *I get here at 7.30am and I only leave at noon. That's how long I sit here.*

The above statement reflects the inconvenience to patients associated with the long hours spent waiting for services. For many patients a sense of disempowerment often accompanies having to wait for services, as they have no alternative but to comply. Perhaps the fact that patients have few options but to wait their turn fosters a sense of alienation with regard to the public health care system. Thus, not only do patients experience the health care system as authoritarian and patriarchal, they also may not feel that they have any recourse when the quality of the treatment they receive is substandard.

While, patients' relationship with the health care system may be a salient feature of their experience and may inform their role in their own treatment process, there are also other, intra-individual factors that may shape the way adherence is thought about. A cognitive understanding of the consequences of poor adherence is one such intra-individual factor.

Concerns about the consequences of poor adherence

Several patients identified a clear mechanistic cause and effect relationship between non-adherence and pursuant medical symptoms. For example, Lydia, stated:

> *I know what can happen because you can fall over along the side of the road or you can get a stroke. Many people have had strokes from high blood. That's why I am very careful. I am scared of strokes and things like that.*

Thus, for this respondent concern and worry about the consequences of adverse medical developments appeared to play an important role in determining the question of adherence. Similarly Elsie disclosed the following:

> *If I have not taken my pills in the morning then I feel that my head is not quite right. Also, if I have eaten too much fatty foods then my head is also not quite right. If you don't take those pills then your blood goes very high and then you can die.*

It appears that patients indeed possessed a cognitive understanding of their illness and were able to identify for themselves the consequences of poor adherence. Such an understanding is in keeping with a mechanistic paradigm, where the aim is to identify and correct the causal factors associated with the deterioration of health. The notion of cause and effect appears to be highly salient in the narratives of respondents.

The question of diet was a highly salient concern in the narratives of the respondents. Again, a direct relationship was identified between dietary deviations and symptoms of illness. For example, Lydia stated:

> *I found out when I had high blood that if I perhaps eat lots of chocolate then I get headaches. Perhaps if I eat a lot of salty food then I can feel the pressure on my head and the blood is high and so I begin to cut these kinds of things out.*

Adaptations of eating habits also featured in the range of concerns that affected respondents. Sugar and fat appeared to feature prominently in the diet of respondents prior to their diagnosis with their illness. As such, these were the areas in which most dietary adjustments needed to be made. For example, Elsie stated:

> *I taught myself to drink bitter coffee and bitter tea. But when I feel a bit weak then I put in a little sugar.*

Floris, a woman in her sixties, told of changes to the fat content of her diet. She stated:

> *I have not really made many changes (to my diet). I just went along with my usual way of eating, just not as much fat. I was very fond of the fattiness.*

Similarly, Elsie stated:

> *Meat and chicken I eat a lot of. But I can feel when I eat too many fatty foods then my head is not quite right.*

Changes to diet had important implications for family functioning, especially when it came to mealtimes. Stella, stated:

> *I have had to change the food I eat. I can't eat with my family.*

For this respondent, not being able to eat with her family was related to the fact that her diet was markedly different from theirs. The fact that she needed to eat different foods suggested that she was in some way seen as apart from the rest of her family members.

Financial problems affecting adherence

One of the most defining features of the sample, indeed of most persons utilising the public health system, was the reality of scare financial resources. While most medication is provided free of charge to patients, other costs associated with procuring medication and travelling to the medical clinic were sometimes prohibitive.

A respondent, Bella, stated:

> *That time the money was scarce and so I couldn't go to the town every time to get my tablets and so on. So I thought let's just leave it.*

Some patients received no illness benefits as part of an employment package as their conditions of employment involved being paid only when they appeared for work. For these patients being absent from work even for a few hours to attend clinic visits had potentially serious financial consequences. For example, Floris stated:

> *You miss a day's wages. So you see money plays a role whether or not I go to the clinic. What do you think?*

In some several cases the cost of the medication was also prohibitive. One respondent, Hendrika, stated:

> *I had to go and buy the pills and then I thought it's a bit much.*

Another considered the notion of spending money on medication unacceptable. He stated:

> *I decided that I would do without the blood pressure pills. I don't see a chance to pay the money at the pharmacy every time. I just don't see a chance.*

Similarly, the cost of a medical consultation, even at a public health clinic, was considered out of the financial reach of participants. One woman stated

> *I said that I would not be able to pay every time. The doctors' fees are very high.*

In addition to the costs associated with medication and clinic visits, adhering to a special diet for diabetes patients was impossible or very difficult financially. One patient with diabetes stated:

> *Then he told me what I should eat. I told him that the things he said I should eat I can't really eat because I don't have the income. My husband gets a disability and my children are all married. Those things he said I should eat are expensive. They are not cheap.*

Thus competing demands on financial resources create significant barriers to the three dimensions of treatment adherence, namely, clinic visits, medication adherence, and adhering to dietary recommendations. Financial barriers associated with these dimensions are not trivial because for many patients they are likely to seriously undermine any health benefits that could potentially accrue from treatment.

Transport problems

Several respondents stated that getting to and from the clinic, where they received medical treatment, or the pharmacy, where they received their medication was extremely problematic. Coupled with the logistical difficulties involved in commuting to work, transport problems for many respondents were a significant impediment to optimising medical compliance. For example, Florense, stated:

> *I have to travel far to get to work. If I have to take a day off to come to the clinic then I can't go to work at all.*

Many patients attending public health clinics in rural or semi-rural areas, such as those in and around Stellenbosch do not have access to either private or public transport. In many instances, living far from the clinic where services are provided is a major impediment to attending clinic visits regularly. For example, Martha, a 70 year old patient stated:

> *I have to walk to the clinic from where I live, which is far.*

Similarly, Evelina stated:

> *I did not want to walk so far and I did not want to go to that clinic. It is far from here. It's hot and I have to struggle through the heat.*

In such situations considerable personal effort is required in order for patient to derive health benefits. Moreover, such benefits may not be directly observable by the patient and thus the effort involved in walking to the clinic and enduring the discomfort of the elements may not be worthwhile for many patients despite their acknowledged need for treatment.

Social support

An important determinant of treatment adherence is social support. Often the logical trajectory between social support and adherence is circuitous, as is represented by the statement by Magdalena:

> *Look, you get different types of people. You get people who make the time to find out what you need. I came to the clinic last week. I had such bad pain and I said that I needed conversation. I needed someone to talk to. People don't understand me so well. And so I came here (to the clinic) and the sister sat with me. She chatted to me so pleasantly. I was very happy. I really felt better (afterwards).*

While it is not indicated that the conversation between the patient and the sister was related to adherence, it is clear that the support provided to the patient was of considerable importance in helping to make her feel at ease with the nurse and therefore with the health care system. The fact that an incident of this nature emerged in a discussion of treatment adherence suggests that a positive relationship between nurses and patients may be directly important to enhance the likelihood of adherence.

Johanna, a 46 year old woman with diabetes, stated:

> *Most of the time Else was there for me. She is my neighbour. She lives opposite me. Most of the time she helped me on the occasions when I was really weak.*

The apparent gratitude expressed by Johanna appeared to be an acknowledgement that the support she received from her neighbour played an important role in the management of her illness. On the other hand, the absence of social support can constitute an impediment to adherence, as noted by Bella who stated:

> *There is no one who helps me in the evenings. I am on my own and have to do everything on my own.*

While the above quotations suggest an oblique relationship between social support and adherence, participants also acknowledged that direct support, advice and counsel from others regarding management of their illness played a important role in their treatment adherence. For example, Bettie, a 36 year old woman with diabetes recounted:

> *One woman whom we work with, she's sick all the time from smoking also. And then we tell each other that we should take our medication.*

Similarly, Lydia, a 57 patient with hypertension, stated:

> *When I started getting high blood, the woman I worked for explained to me told me "Lydia, you must not use much salt in your food", and she actually, you can say, put me on a diet.*

The above quotation suggests a relationship with an employer that extends beyond a traditional employer-employee relationship. Thus, while such a relationship appears to be valued by the patient and is seen by her as working in her best interests, the fact that she was "put on a diet" conveys a sense of an authoritarian relationship between the employer and the employee.

The question of diet is also related to social networks as eating together can be a concern for some patients. Social networks appear to be integral to the creation of environmental conditions for proper adherence to dietary recommendations. An environment in which the family as a whole creates conditions to optimise adherence is likely to be more beneficial to patients than one in which the patient has to adhere to a diet alone. In the following case, a diet in keeping with the requirements for hypertension has not been integrated into family practices:

> *My family eats other kinds of food. Sometimes when the finances are a problem then I have to fall in with them and then what I do is I eat smaller portions. So lets say dish a plate of food for them, I will dish a smaller plat for myself.*

On the other hand, several patients that instances in which family members played an important role in helping them adhere to treatment. Lena stated:

> *They (my children) help me yes. They tell me when I eat the wrong food.*

Later during the interview she also stated:

> *My husband helps me to remember (to take medication). He has high blood yes and he has asthma.*

Similarly, Johanna, a 46 year old woman with diabetes stated

> *He (my husband) is very much on to the idea that I have to eat correctly. A person tends to eat wrongly in between meals. He stands by me and he helps me.*

When asked specifically about the role her family plays in helping her with her hypertension, Magdalena, a 52 year old woman stated:

> *I don't know. I don't think they understand. My children. I don't actually want to tell them I am a very sick woman.*

In the above case the respondent appeared not to want to tell her family specific information about her illness. In some cases such reluctance is related to wanting to protect family members from such knowledge. In other cases it is due to a difficult relationship that patients may have with their family. In either case, disclosing to family members the specifics of the illness is likely to be associated with high treatment adherence.

Spirituality

Within the sample several respondents made reference to their spirituality as a resource that helped them cope with the challenges of having a chronic illness. Spirituality appeared to play an important role in providing respondents with a context within which to locate their experience as a patient with a unique range of considerations. For example, Floris, a 59 year old pensioner with diabetes, stated:

> *I don't really want to say that a person should convert but I am a religious person and I rely very much on the Lord for leadership. When I get depressed then I just ask, Lord, it's your turn now. You must give me leadership now.*

Similarly, Stella, a 42 year old woman with diabetes stated:

> *I took the pills for about a month and then I stopped because I was converted. I trusted that the Lord would be my doctor. But the Bible also says you must obey the earthly rules. That's why I take my pills.*

Also, Jessica stated:

> *I come to the clinic regularly because the Bible says that obedience is better. But I trust that the Lord will look after me. The Lord has his own time.*

The question of obedience to authority, which was represented by medical providers, also featured in the narratives of several respondents when they mentioned their spirituality. Obedience, combined with trust that God would look after the patient comprised the way in which patients constructed the role of religion in determining their level of adherence.

Alternative medicine

Among the cultural aspects that uniquely characterise the present sample is the notion of alternative medical practices, which appear to have considerable credibility among respondents. For example, Florense, a 42 year old woman with hypertension who worked as a char, stated:

> *For the past five months I have been taking herbal medicine. The old people always said that we should pick the wild marijuana and drink this. But it does not work very well.*

Reliance here on knowledge derived from elders is considered as valuable, except that the effectiveness of their recommendations is seen as poor as symptoms are not controlled by alternative medical means. Similarly, one patient indicated that alternative treatment is sometimes selected in place of traditional treatment. She stated that:

> *I heard that some people take herbs and then they don't take their pills. I tried it but it did not work for me.*

The above quote emphasises that the credibility of alternative treatment available in the context in which the sample resides is juxtaposed with the respondent's own experience regarding the effectiveness of such treatment.

Understanding of the reasons for poor adherence

Participants were asked to offer reasons for the fact that some patients, including themselves, did not adhere to treatment regimens as prescribed by their health providers. From within a logical and mechanistic paradigm, treatment adherence constitutes volitional behaviour that conforms to patients' reason and rationality. Some of the responses from participants to the question of reasons for non-adherence could be understood from within a mechanistic paradigm. For example, one participant stated:

> *It's forgetfulness. You think you're OK and then you skip one.*
>
> *You go for your pills and then you think oh well I feel alright and then you don't take any.*

The above respondent cited a combination of forgetfulness and the absence of symptoms as reasons for not taking her pills. Indeed, for many respondents the fact that they had no symptoms was often a reason for not taking their medication as prescribed. In addition to the absence of symptoms, some respondents stated that their medication might be addictive, which was a reason that caution needed to be exercised regarding total adherence. One respondent stated:

> *Some people don't like to take the pills all the time because it's almost like a drug, you see, to take medicine all the time. People become dependent on their medication.*

The sentiment described above may be in part be related to the fact that substance abuse is widespread in many communities from which the sample was drawn. Thus, participants' reluctance to take their medication as prescribed may be seen in terms of the stresses undergone by their communities that were characteristic of social and cultural marginalisation.

Besides forgetfulness and the absence of symptoms certain physiological reactions were associated with taking medication. One respondent stated:

> *Sometimes we tell each other we will not take the water pill because it makes us pee a lot. So one has to go to the toilet a lot.*

Thus, the discomfort accompanying immediate physiological reactions associated with medication adherence such as frequent urination were seen as intolerable in the context of a disease that was not obviously symptomatic. In the above instance, the cost of adherence appeared to outweigh the potential benefits associated with treatment adherence. Please see Appendix II for a summary table of the above data.

Conclusion

Various dimensions of the respondents' experiences as patients emerged in the interviews. These dimensions included attribution of the origin of the illness, respondents' subjective experience of the illness, their relationships with the public health system, the manner in which they thought of the consequences of poor adherence, financial problems they experienced and how these affected adherence, transport problems, social support, spirituality, the question of the viability of alternative medicine, and attempts to explain the reasons for poor adherence. These dimensions of experiences are unique in that they represent the concerns of patients who have had first-hand experiences with the public health system. Moreover, the fact that these data were obtained in the context of open qualitative interviews using open-ended questions indicates that they were elicited without a priori assumptions from either the interviewers or the investigator. To this extent the data may be considered to represent the concerns and opinions of participants unencumbered by the limitations imposed questionnaires or psychometric measures. The use of semi-structured interviews instead of structured interviews or psychometric measures minimises the extent to which demand characteristics play a role in defining participants' responses. The analysis that ensues in the following chapter represents an effort to examine the results of the investigation within the context of the post-apartheid public health care system.

CHAPTER 6

DISCUSSION

Relationship between the patient and the health care system

An appropriate quotation that locates the present study within a social and historical context is one by Hippocrates who stated: "the physician should keep aware of the fact that patients often lie when they state that they have taken certain medicines" (quoted in Lasagna, 1973). The statement reflects a sense of suspicion and scepticism that health care professionals may hold about patients that may have developed in part through interactions with patients in the context of a hierarchical relationship.

As has been argued by Trostle (1988), the notion of compliance or adherence is based on the assumption of a dominant professional who gives advice or orders, and a dependent layperson who executes those orders. Thus compliance and its modern term, adherence, form part of an ideology based on assumptions about the proper relationship between doctors and their patients. Non-adherence potentially marks a patient's "'misbehaviour' as being outside the boundaries of a physician's responsibility" (Trostle, p. 1305). The term "non-adherence" rationalises physician withdrawal and blames the patient rather than promoting a re-examination of clinical priorities. By conceptualising patients as misbehaving, a rationale develops for them to be scolded or considered to be "naughty", as was the case with Stella and Elsie in the present study. The admonition of patients and the process of framing them as being disobedient or badly behaved assumes a relationship between the health care provider and the consumer of health services that is hierarchical and uni-directional in terms of the flow of power.

Trostle (1988) argues that patients may be clinically non-adherent for a variety of reasons. Firstly, a patient may disagree with the clinical advice of his or her provider. In the case of Lena, such a sentiment was expressed in her dissatisfaction with her perception that she was not adequately examined but was instead simply prescribed treatment. Her reluctance to take her medication appeared to be driven by the fact that her medical problem had neither been identified by her medical provider to her satisfaction nor properly explained to her.

Secondly, according to Trostle (1988), clinical non-adherence may also likely result from a series of social realities competing with the clinical agenda, such as financial constraints, being labelled a patient, inability to function adequately under a medication's side effects, familial opposition to therapy. These social realities may therefore dislodge adherence to treatment recommendations as a salient matter for the patient (Trostle, 1988). Among several members of the sample, financial constraints were repeatedly named as an important factor that affected adherence. The manner in which employment relationships were structured was in part responsible for creating financial constraints. For example, receiving remuneration only for the number of hours worked created situations in which many people simply could not afford to take the time away from work to meet clinic appointments or collect medication. By doing so, it was likely that they would lose a whole day's wages, as the transport infrastructure in the communities from which the sample was selected was sub-standard. Thus, many hours would have to be spent travelling to appointments, waiting to be attended to by the nursing staff, and then travelling back to work. In addition to these constraints, participants complained that the cost of purchasing medication was similarly prohibitive. While officially medication for chronic illnesses is supposed to be provided by the provincial health care system free of charge, several participants reported during the interviews that they were made to pay for their medication and that this was expensive for them.

Thirdly, clinical non-adherence may be an expression of the patients' rejection of medical intervention altogether. This rejection was likely to be true in the case of the participant who indicated that she was reluctant to take her pills because she likened it to a drug. She gave as a possible reason for being non-adherent the concern about becoming addicted to or dependent on her medication. An important consideration among patients who express concerns about the habit-forming potential of medications for chronic conditions is the notion of health literacy. Low levels of health literacy have been implicated in cases in which patients' adherence levels decrease as the physical symptoms associated with their illness diminish (Turk, Salovey, & Litt, 1986). Consequently, little impetus exists for the continuation of optimal adherence in the absence of symptoms. Health literacy may also apply to common misconceptions about the effect of medication aimed at controlling chronic illnesses. One of these misconceptions is that these medications may be habit-forming. While medications for hypertension or Type II diabetes are not known to be habit-forming, the fact that such a perception exists among patients suggests that health literacy as a construct may be implicated. It is possible that concerns about the habit-forming possibilities of certain drugs may be informed by the widespread substance abuse that is prevalent among many historically disadvantaged communities. Thus, contextual realities about substance dependence may in part drive treatment non-adherence among some patients. This hypothesis requires additional research to be substantiated.

Attribution of responsibility for the causes of and solutions to medical problems

While relationships between health professionals and patients are of considerable importance in furthering an understanding of the question of treatment adherence, also important are considerations regarding attributions that are made about responsibility for causes and solutions to medical problems. Brickman, Rabinovitz, Karuza, Coates, Cohn, & Kidder (1982) have identified four general models that are informative in conceptualising attributions of responsibility for the causes and solutions to health problems. The models identified by these authors are the moral model, the compensatory model, the medical model, and the enlightenment model.

The moral model states that people are responsible for both their medical problems and the solutions associated with them. For example, excessive alcohol consumptions is seen as a sign of weakness, requiring drinkers to exercise willpower. The compensatory model states that people are not responsible for their medical problems but are responsible for the solutions associated with these problems. Patients suffer from medical illnesses not because of their own deficiencies but from the failure of their social environment to provide them with goods and services to which they are entitled. Thus, to solve these problems patients need to become assertive in ensuring that they obtain what they require to restore themselves to health.

The medical model states that people are not held responsible for either the origin of or the solution to their problems. Patients according to the medical model are a collection of organs that can malfunction or become infected. Thus neither the illness nor the treatment is the patient's responsibility. Patients are expected to accept their illness and are responsible for seeking and using expert help. Experts, usually doctors and in the case of the South African public health system most likely nurses, are considered necessary to bring about positive change as these professionals have been trained to diagnose and treat the problem. The medical model may foster dependency, as patients are not considered to be responsible for either their medical problems or solutions to these problems. The enlightenment model states that patients are responsible for their medical problems but not responsible for solving them. Alcoholics Anonymous is considered a successful example of the enlightenment model as it requires participants to take responsibility for their drinking and to admit that it is beyond their power to control their drinking without help from others. The table presented in Appendix III represents a summary of the model articulated by Brickman et al. (1982)

In many ways the medical model is most dominant in the public health care system in South Africa. Participants in the study attributed the origin of their illness to a variety of sources. For example, both Elsie attributed the origin of her diabetic condition to family genetics and to the fact that she had given birth to two children. Similarly, Dorie attributed her condition of hypertension to having been pregnant and Lauretta made the assumption that hypertension was an inherited illness. Thus for these respondents their attribution to themselves of the cause of their medical condition was low, as was the attribution to themselves for the solution of the problem. In one case a participant stated that becoming angry with someone could cause hypertension. To some extent this attribution may be associated with the common misunderstanding that hypertension involves people becoming overly tense, i.e. "hyper tense", rather than elevated blood pressure. Nonetheless, this respondent appeared to attribute responsibility for her hypertension to her own psychological condition of elevated stress, but the solution to the problem to the health care system, which is in keeping with the enlightenment model as explicated by Brickman et al (1982).

Several respondents in the sample referred to their religious beliefs and their relationship with God. For example, Floris indicated that she prayed to God for leadership or guidance, thus locating the responsibility for her recovery and well being outside of herself. Religious faith had one of two effects on adherence. Stella stated that she trusted that her religious faith would ensure that she remained healthy and thus did not see the need for medication adherence. On the other hand, Jessica interpreted the Bible to indicate that she needed to be obedient to her doctor and thus made a conscious decision to resume taking her medication. At a proximal level, Jessica located the responsibility for the solution to her medical condition within herself, while at a distal level this responsibility appears to be attributed to what she referred to as injunctures from "the Lord." Thus, among persons who attributed much of their behaviour regarding adherence to their religious faith, Brickman et al's model may have limited applicability.

Appraisal of the consequences of poor adherence

In an effort to understand the manner in which individuals construct meaning regarding health, illness and well-being, a focus on theories of worldview is appropriate. The concept of worldview has been applied to the way in which health, illness, and disease are conceptualised and in which treatment options are considered. Nicholas and Gobble (1991) define worldview as a frame of reference from which one perceives the world and a method of organising and ordering information about the nature of events. Worldview theory has informed the way in which individuals understand and apply the concept of health, illness and disease to their lives (Poppe, 1995). A prominent worldview theory is one articulated by Pepper (1942), whose work has influenced health psychology research. Pepper (1942) proposed that people may hold one or more of four possible perspectives with which they may view the world. These worldviews are formism, mechanism, contextualism and organicism.

The formistic worldview suggests a categorical way of thinking and its root metaphor is similarity. Objects, experiences, events and people are categorised and classified according to the way in which they are similar. The formistic worldview is based on binary opposition and dualistic thinking. In terms of health individuals are conceptualised as being either sick or healthy, or afflicted with a disease or not afflicted with it (Nicholas and Gobble, 1991). Adherence in terms of the formistic worldview is seen as a categorical phenomenon as patients are deemed either adherent or non-adherent. In reality however, there may be varying degrees of adherence and individual patients may go through periods of higher and lower levels of adherence in more than one aspect of their treatment regimen. Moreover, there may be different criteria for measuring adherence, depending on the perspective of the person. Thus health workers, patients, family members, and friends of the patient may all hold varying views of the patient's degree of adherence. Thus, the formistic worldview is likely to limit an appropriate conceptualisation of adherence as it applies to respondents in the sample.

The mechanistic worldview suggests a causal and linear method of thinking and its root metaphor is the machine. Since machines comprise parts and sub-parts that operate together, the mechanistic approach is to reduce the whole system to its smallest parts, which are then subjected to scrutiny. Thus the mechanistic worldview seeks to discover a linear relationship between cause and effect. In terms of health and illness human beings within the mechanistic worldview are considered to be passive and function as machines. The objective is to identify and isolate the causal sequences that lead to illness and presumably to health (Nicholas & Gobble, 1991). In many respects the notion of adherence to medical and behavioural regimens as a means of controlling medical symptoms forms part of a logical and mechanistic understanding of health. Thus, in terms of the mechanistic worldview, the onus is on the health provider to convince the patient of the importance of adherence so that its effect can be felt in terms of health and well being.

The root metaphor of the contextual worldview is the historical event and the emphasis is that events should be considered within their setting and context. The contextual worldview rejects the notion that reality is fundamentally external and stable and that human thought is separable from meaning and action. By implication, health and behaviour are also regarded as inseparable and independent (Mahoney & Lyddon, 1988). Cognitions, affect and behaviour therefore play an integral role in the development of illness and in facilitating the healing process. The contextual worldview is most appropriate in conceptualising treatment adherence within the lived experienced of members of the sample and in considering the limitations and strengths they experience in their every day lives. Thus, rather than thinking in terms of cause and effect, a contextualist perspective aims to understand the unique life circumstances of patients within the context of their history and present life circumstances. A contextualist perspective of the patient emphasises the relationship between the health care system and the individual characteristics of the patient, within the context of his or her experience of social marginalisation as formerly disadvantaged South Africans.

The final worldview identified by Pepper is organicism and its root metaphor is the living organism. The whole living organism is seen as comprising a unique synthesis of all its sub-parts, and the absence of a single component may fundamentally alter the final composite. The organism is also seen as constantly interacting with its environment in a dynamic and evolving manner. In relating the organismic worldview to health and disease, Brody and Sobel define health as the ability of a system to respond adaptively to a wide variety of environmental challenges (for example, physical, chemical, infectious, psychological, and social). Disease on the other hand is the failure of the organism to fashion an adaptive response to environmental challenges. Hence a disruption occurs in the overall equilibrium of the system. If treatment adherence represents an effort to restore equilibrium to the patient's constitution, then suboptimal adherence may be a manifestation of disequilibrium in terms of the organismic worldview.

In terms of identifying the causes of poor adherence, Lydia, one of the members of the sample, whose attribution of the consequences of poor adherence included stroke or falling over on the side of the road, suggests a mechanistic worldview. Similarly, Elsie indicated acute awareness of the consequences of poor adherence such as death resulting from high blood pressure or her head not being "quite right". An alternative appraisal of the consequences of poor adherence may be not to conceptualise this construct as a consequential matter at all and to avoid considering adherent behaviour from within a mechanistic paradigm. From an organismic perspective, individuals continue to strive towards equlibrium. The assumption therefore is that behaviour and health are systemically linked within the historical and social context of social disadvantage and marginalisation in which patients find themselves. It then follows that adherent behaviour, as it may be operationalised for each individual patient, may be seen as a contextual phenomenon that is more complex than simply a series of actions to offset physical discomfort such as those associated with stroke, headache, or elevation in blood pressure. Thus, rather than a reaction to the possibility of a downward spiral in health, a contextual and organismic worldview may consider adherent behaviour as health promoting in nature, as people continue to strive for optimal health and wellbeing (Kagee & Dixon, 2000).

Social support

Social support refers to the "information, clarification, assistance, and reassurance that an individual receives from others" (Friedman, p. 13). There is considerable evidence to suggest that positive social support is associated with positive health outcomes. In their review of several large studies of social support and health (House, Landis, & Umberson, 1988) concluded that the risk of mortality is higher among individuals with fewer supportive contacts. Similarly, in a review by Hogan, Linden, & Najarian (2002) found that effective social support promoted better health outcomes. Three forms of social support have been associated with enhancing positive health outcomes. These are tangible support such as goods such as money, food, or child care; informational support such as advice or offering an alternative perspective; and emotional support that may include reassurance that the patient is cared for and valued by others (Coyne et al, 1981; House, 1981; Wills, 1984).

With regard to adherence, Caplan, Robinson, French, Caldwell, Shinn (1976) defined social support as encouragement from family and friends to carry out the treatment regimen. Encouragement of this nature may be helpful to the patient to increase his or her feelings of self-competence and motivation to engage in adherent behaviour. Magdalena's need for someone to talk to and later her experience of the company of her nurse as supportive was presumably related to a sense of connectedness with others, leading to a decreased level of psychological distress. Her reference to her need to be understood was only peripherally related to adherence, but the fact that this need was met played an important role in helping her attain a sense of being part of a social system in which she felt valued. Similarly, Johanna's experience with her neighbour helped her benefit from both tangible and emotional support, while Lydia's comment on the advice she received from her employer indicated a reliance on informational support. A particular form of social support, namely spousal support has been shown to be associated with low levels of depression, with higher motivation to adhere to treatment, and a greater level of knowledge of the treatment regimen (Caplan, et al, 1976). Members of the sample indicated that support from their spouses was helpful to them. For example, Lena stated that both she and her husband had chronic illnesses and that they provided mutual reminders to each other regarding their medication. Similarly, Johanna indicated the important role of her husband in helping her maintain a healthy diet. Conversely, the absence of social support as expressed by Bella indicated a sense of dejectedness and alienation that that was clearly a source of distress for her.

In addition to support from individual family members and friends, the notion of a "psychological sense of community" (Sarason, 1974) is also relevant to patients' sense of connectedness. Campbell (2003) has argued that a community that enables health is an important precondition for behaviour change directed at optimising health outcomes. The notion of a health-enabling community refers to a context that promotes the renegotiation of social identities and the empowerment of community members. One of the features of a health enabling community is the notion of social capital. Social capital refers to the level of participation that community members have in local networks and organisations (Campbell, 2003). Communities that have high levels of social capital are characterised by interpersonal trust, help and support that are reciprocated, and a strong positive local community identity (Baum, 1999). The assumption is that people living in communities that have high levels of social capital are most likely to have high levels of perceived control over their lives (Campbell, 2003) and are thus more likely than not to take control over their health. The implications for treatment adherence flow from these assumptions.

Whether high levels of social capital exist in the communities from which the sample is drawn is unclear. On one hand these communities are largely poor and have been socially and politically marginalized. On the other hand members of the sample mainly appear to have strong positive interpersonal relationships. The data collected for the present study are most likely to offer only limited insights into the question of social capital. Yet, this matter remains a necessary one to consider when conceptualising the extra-individual determinants of adherence.

Financial problems affecting adherence

Respondents indicated that financial considerations and relatedly, transport problems, had a significant impact on adherence. In many ways the social context characterised by limited community resources such as a poor transport infrastructure played a role in determining patients' clinic attendance. Moreover, the manner in which work was organised for some of the respondents determined the extent to which it was possible for them to attend clinic appointments. The piecemeal nature of work and the fact that some members of the sample were paid only for the hours worked, combined with long travelling distances created unique difficulties that necessarily require conceptualising adherence as more than a series of volitional acts by single individuals. Instead, contextual realities and environmental conditions characteristic of impoverished rural environments created among respondents potential barriers to optimal health service delivery, health care and treatment adherence.

Conclusion

The present study represents an effort to elicit data from respondents from their own perspectives by means of a description of their thoughts and experiences regarding their illness and adherence to treatment recommendations. As treatment adherence is not simply an individual volitional act that conforms to objective and rational logic, a qualitative approach was most appropriate in gaining an understanding of the realities that members of the sample faced regarding adhering to treatment regimens that were often difficult and uncomfortable. The methodological approach of this study afforded the opportunity to give a voice to respondents beyond what may have been possible in a quantitative study that used psychometric instruments. Thus attributions respondents made to their illness, their experiences with the public health system, their understanding of the consequences of poor adherence, financial and logistical concerns, and concerns regarding social support are potentially important issues that will assist in developing a comprehensive understanding of the reality of persons with chronic illnesses attending primary care clinics.

Limitations of the study

The present study represents one of the first attempts to systematically collect data on treatment adherence from a semi-rural sample diagnosed with chronic illnesses attending primary health clinics in the Western Cape. The small sample size does not permit generalisability of the data to the population of patients seeking treatment at public health clinics in the Boland. Instead, data yielded from this research may be useful in identifying the salient issues faced by patients, which may be validated by later studies. While the same two interviewers collected data in all the interviews, the fact that they were middle class White women, and therefore demographically different from the individuals in the sample may have been an impediment to ensuring candid responses from participants. However, the interviewers were trained in how to conduct qualitative interviews and to be attuned to interpersonal dynamics when collecting data of a sensitive nature.

Significance and future directions.

The present study yielded data on the behavioural, psychological, and social correlates of treatment adherence in a sample of patients attending primary health care clinics in the Boland. These data offer an understanding of the perceived barriers to treatment adherence from the perspective of patients. The implications for future research include developing a measurement instrument to be administered to a larger sample in order to validate the data collected in the qualitative study. Both qualitative and quantitative data may be used to develop potential interventions designed to enhance adherence among patients in historically disadvantaged communities. The ultimate result of this line of research is to maximise the effectiveness of health interventions, thus contributing to patients' well-being and quality of life and maximising optimal usage of the already overburdened South African health care system.

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APPENDIX I

Interview Questions

1. Tell me about your experience with your illness.
2. What does it mean to you to have this illness?
3. How has your life changed as a result of your illness?
4. Who supports you with your illness.
5. How has your illness affected your relationships with your family members?
6. What is your experience of the health system, the nurses and the doctors?
7. How do you feel about taking the treatment for your illness?
8. Why do you think some people do not take their medication?

Further questions and probes depended on how the conversation unfolded and how much the person spoke.

APPENDIX II

Summary of emergent themes

Theme	Examples
Attribution of origin of illness	• Onset after pregnancy. • Onset due to psychological state.
Experience of illness	• Resigned acceptance to illness. • Physical pain associated with illness.
Experiences with public health care system	• Admonishment from clinic staff. • Dissatisfaction due to not being. properly examined and attended to by clinic staff. • Experience of being infantilised by clinic staff. • Long waiting periods at the clinic.
Concerns about the consequences of poor adherence	• Fear of stroke due to hypertension • Headaches and pressure in the head. • Difficulty in negotiating social aspects of eating such as family meal times.
Financial problems affecting adherence	• Cost of transport to the clinic. Missing a day's wages due to clinic visit. • Cost of medication. • Cost of clinic fees. • Cost of food required for diet.

Theme	**Examples**
Transport problems	• Long travelling distance. • Absence of public transport.
Psychosocial support	• Social support from nursing staff. • Practical support from neighbours and friends. • Practical support from employer. • Encouragement from family and spouse around diet.
Spirituality	• Drawing strength from spiritual beliefs. • Obedience as part of religious duties.
Alternative medicine	• Reliance on herbal medicine.
Understanding reasons for poor adherence	• Forgetfulness. • Absence of symptoms. • Concern about dependence on medication. • Side effects of medication.

APPENDIX III

Summary of the model developed by Brickman, Rabinovitz, Karuza, Coates, Cohn, and Kidder (1982).

	Attribution to self of responsibility for solution	
	High	**Low**
Attribution to self of responsibility for the health problem.		
High	Moral Model	Enlightenment Model
Low	Compensatory Model	Medical Model