Journal of Health Psychology
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*J Health Psychol* 2007 12: 444
DOI: 10.1177/1359105307076232

# Treatment Adherence among Primary Care Patients in a Historically Disadvantaged Community in South Africa

## A Qualitative Study

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*Journal of Health Psychology*

Los Angeles, London, New Delhi and
Singapore, www.sagepublications.com
Vol 12(3) 444–460
DOI: 10.1177/1359105307076232

## Abstract

The present study examined the issue of treatment adherence among a sample of 23 rural South African patients living with either hypertension or diabetes, or both. The sample was asked to participate in qualitative interviews that asked about various aspects of their experience of their illness and treatment. The analysis of the data focused on the content of participants' concerns and difficulties with adhering to treatment recommendations. The themes that emerged from the study were participants' attribution of the origin of their illness, their subjective experience of their illness, their concerns about the consequences of poor adherence, financial problems and psychosocial support.

COMPETING INTERESTS: None declared.

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## Keywords

- *primary care*
- *South Africa*
- *treatment adherence*

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 in developing countries are poorly understood. The present study examined 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 was 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.

## The complexities of studying adherence

The reasons for suboptimal treatment adherence among medical patients have puzzled researchers for many years. Indeed, there is growing evidence suggesting that a number of drugs, combined with modifications to lifestyle, have the potential to improve health significantly (Vermeire, Hearnshaw, van Royen, & Denekens, 2001). Yet, only 50 per cent of professional advice is likely to be taken up by patients (WHO, 2001). Poor patient adherence to professional medical advice has wide-ranging consequences that include medical and psychosocial complications associated with disease, compromised quality of life and a wastage of health care resources (Cleemput & Kesteloot, 2002).

Three major themes appear in the medical literature associated with non-adherence to therapy, namely, the factors associated with non-adherence to treatment, successful prediction of potential non-adherent patients and methods of intervention by health providers to enhance adherence to treatment (Dick, 1994). Within the traditional biomedical perspective, the patient is viewed as a recipient and performer of regimens that are to be accepted and obeyed (Trostle, 1988). This perspective has led to research into the demographic and personality characteristics associated with non-adherent patients. More than 200 variables associated with treatment adherence have been identified (Anonymous, 1997), some of which are also associated with health provider and health facility factors (Lewin, Dick, Zwarenstein, & Lombard, 2005). Various studies have shown the association between demographic characteristics such as gender, age, ethnic groupings, level of education and income with non-adherence to therapy. However these variables are not inherently causal but tend to act as proxies for other factors such as health literacy, poor financial resources to access health care and cultural mistrust of the formal health sector.

The biomedical perspective of treatment behaviour is limited by the reality that many of the cited determinants of adherence are unalterable. Thus the tendency to demonstrate a consistent association between these factors and adherence does not lead to an approach to remedy the situation. First, much of the time, disadvantaged members of society exhibit many of the 'risk factors' identified by biomedical research. Second, demographic, physiological and other characteristics of patients do not necessarily relate to patients' motivation or intentions, nor do they explain why some patients adhere to treatment despite multiple adverse characteristics. Third, the medical model of adherence relies on a reductionist method of selecting characteristics for study, rather than developing a unified conceptual approach to adherence in treatment behaviour.

Most biomedical research is empirical in nature, which is the traditional approach of epidemiologists and medical researchers. The pragmatic biomedical approach may be contrasted with questions framed by social scientists who try to understand the complexity of treatment behaviour within contextual and socio-cultural dimensions. The social science perspective questions many of the assumptions on which the epidemiologists and health systems researchers have based their studies, but is itself criticized as it may not always offer contributions of direct practical value to policy makers systematically attempting to improve the quality of health care delivery.

Qualitative research conducted by social scientists has highlighted a growing recognition that the interests of those who provide health care do not necessarily coincide with the needs of those who use it (Harrison, 2003). A recent systematic review synthesizing qualitative studies of lay experiences of medicine taking has highlighted the widespread caution that lay persons have of taking medication (Pound et al., 2005). The review noted that lay persons expressed concerns about developing dependence, tolerance or addiction to medication prescribed for chronic conditions. Patients frequently reported reducing their doses without consulting their health care providers. The review showed that many patients frequently adopted alternative therapies to supplement the medical treatment they were already receiving. Lay people did not view medicine as something to be taken 'as prescribed', but rather as a resource for use as they saw fit. The review also showed that patients perceived their medication as impacting their identity, experienced problems associated with the disclosure of their illness and suffered stigmatization associated with their medical condition (Pound et al., 2005).

Treatment regimens for conditions such as hypertension and Type II diabetes usually require strict adherence to instructions (Pladevall et al., 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 Organization, 2003). These details are of crucial importance in maximizing 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). 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 Organization, 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 maximize health outcomes.

## Factors associated with adherence

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.

Various factors have been identified in the literature as having important 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 utilization and benefit to patients.

## Social and economic factors

Social and economic factors often combine to yield poor adherence outcomes. Among an indigent sample Simoni, Frick, Lockhart and Liebovitz (2002) 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 the stresses associated with poverty and difficult life circumstances, obviate an acknowledgement of the importance of complying with treatment regimens (Simoni et al., 2002). 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 among 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 characterized by poor educational opportunities, health literacy is likely to be low, accounting in part for low levels of adherence.

## Social support

Considerable research has demonstrated consistently that social support is a strong predictor of medical adherence (e.g. Bearman & La Greca, 2002; Simoni et al., 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 the patient, has also been shown to be strongly associated with adherence (Ciechanowski, Katon, Russo, & Walker, 2001). Data obtained by Roberts (2002) 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 in authority, in possession of specific expertise and in whom the patient invests hope for assistance in the recovery process (Bury, 2004). There is also evidence of a relationship between the functional health literacy of patients and the quality of the physician–patient communication. For example, among a sample of diabetes patients robust bivariate and multivariate relationships were observed between functional health literacy and reports of physician–patient communication (Schillinger, Bindman, Wang, Stewart, & Piette, 2004).

## Other psychological factors

In addition to the psychosocial factors mentioned earlier, considerable evidence suggests that mental status, specifically depressive illness, plays a role in treatment adherence (e.g. Kilbourne et al., 2005; Kim, Han, Hill, Rose, & Roary, 2003). Among general medical patients, DiMatteo, Lepper and Croghan (2000) found that depressed patients were three times less likely than non-depressed patients to adhere to medical treatment.

Attitudes and beliefs about normative behaviour have also been shown to play a role in adherence. Attitudes towards treatment adherence are a person's evaluative opinions, both positive and negative, of the outcome of a health behaviour (O'Boyle, Henly, & Larson, 2001; Ogden, 2000). In general, a positive attitude towards a health behaviour is associated with its practice while a negative attitude is not (Horne, Clatworthy, Polmear, & Weinman, 2001). Subjective norms have been demonstrated to be a robust predictor of health behaviour intentions (Finlay, Trafimow, & Jones, 1997), while self-efficacy to engage in health behaviours has been shown to be strongly associated with a healthy lifestyle in the general population (Gillis, 1993), among patients with diabetes (Syrjälä, Ylöstalo, Niskanen, & Knuuttila, 2004) and among those with hypertension (Ogedegbe, Mancuso, Allegrante, & Charlson, 2003). Subjective norms refer to a person's evaluation of others' (usually family and friends) expectations of a specific behaviour (O'Boyle et al., 2001). The concept of subjective norms is based on the assumption that social pressure encourages people to behave in a socially desirable manner and that people are in turn motivated to comply with these social expectations (Ogden, 2000).

There has been some critique of the tendency of social scientists to focus on individual psychological predictors of adherence such as attitudes and beliefs, without gaining a rich understanding of the contextual realities of persons living with chronic illness. The present study aims to arrive at such a contextual understanding of patients attending South African public health clinics.

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 to 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.

## Method

### Research setting

The 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. In 2004 the total population of the municipality was

103,756 of which 16,297 were African, 58,107 were 'Coloured', 26,999 were White, 284 were Indian and 2069 were categorized at 'Other' (Local Government in South Africa, 2002–2004).

### Participants

The population from which the sample for the present study was selected consisted of patients diagnosed with Type II diabetes or hypertension attending four primary health care clinics located in the Boland area of the Western Cape province of South Africa. The clinics were staffed mainly by nurses, with a medical doctor who visited one day per week. The clinics provided a range of basic services that included the management of chronic illnesses, immunization, family planning and tuberculosis treatment. These services were typical of most clinics serving the public in the Boland area. 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. 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 30 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. Table 1 reflects the gender, illness conditions and occupational status of the sample.

*Table 1.* Gender, illness conditions, and occupational status of the sample

| | *N* |
|---|---|
| *Gender* | |
| Male | 3 |
| Female | 20 |
| *Diagnosis* | |
| Diabetes | 3 |
| Hypertension | 14 |
| Diabetes & Hypertension | 6 |
| *Occupation* | |
| Housewife | 15 |
| Pensioner | 2 |
| Jobs | 6 |

### Procedure

A research assistant approached patients 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 the details of the study were explained to them and asked to sign an informed consent form. A shopping coupon was offered to patients as an expression of gratitude for their participation. 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.

## The interview process

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. 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. The emphasis was not on the actual prescribed regimen but rather on the extent to which patients followed it. 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.

### Analysis

Interviews were recorded, transcribed and entered into Atlas.ti, a computer program 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 coding frame was not stated a priori. Instead, the data were examined in an open-ended manner so that the voices of the respondents could emerge.

As the text was read, excerpts were coded in terms of how they related to the question of respondents' concerns regarding adherence.

The analysis of the data focused on two aspects: (1) the manner in which the narratives were structured, i.e. their essential elements; and (2) the content of the participants' present experiences and concerns. The analysis was conducted using the categorizing process in thematic content analysis (Glaser & Strauss, 1967). This process of categorization involved open coding, selective coding, comparison and categorization and re-reading and modifying. In open coding interview transcripts were repeatedly read and key issues mentioned by respondents were noted. In selective coding key phrases, statements and comments were labelled and categorized according to their content with the assistance of Atlas.ti. Categories were then created by identifying similarities and differences in the content of the statements that were labelled. Finally, we modified the structure of the findings by re-reading the original narratives and modifying the analysed data accordingly.

Atlas.ti was used to call up all the linked data within each category for the final examination to ensure that the model developed in the analysis indeed accurately represented the data. The above process resulted in the identification of a composite list of overarching themes that represented the concerns, issues and problems that respondents associated with adherence to their treatment recommendations.

## Results

Most participants were keen to tell their stories and were responsive to cues and prompts from the interviewers. The narratives that emerged were of three discernable types: Experience of the Illness, Concerns related to Adherence, and Psychosocial Issues related to Illness and Adherence. Six themes emerged from the data that were related to these narratives. The themes 'Attribution of the origin of the illness' and 'Experiences with the health care system' were related to the Experiences of the Illness narrative. The themes 'Concerns about the consequences of poor adherence' and 'Financial problems affecting poor adherence' were related to the Concerns Related to Adherence narrative. The themes 'Transport problems' and 'Social support' were related to the Psychosocial Issues narrative.

### *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. For example, Ella, a 45-year-old mother of four children, 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, Petra, a 46-year-old mother of three stated: 'The high blood is probably from when I was pregnant and they realized that I have sugar (diabetes). 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 (Roberts, 1993). 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, HeRonelle, 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.' The various attributions that respondents indicated regarding the origin of their illness conditions, namely pregnancy, anger and heredity, were likely to play a role in the manner in which they were conceptualized. Such illness conceptualizations in turn affected the way that adherence was thought about and implemented.

### *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 were the main interface between patients and the health care system, shaped the way in which respondents thought of the question of treatment adherence. Chrissie, a 61-year-old woman who appeared to have considerable insight 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. Ronelle, a 51-year-old woman who was particularly affected by the way she was treated by the health system 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 simply to 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 of patients 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. Della, a patient with hypertension, told of how she was infantilized by the health system. She 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 appeared to have the right to admonish 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. Ella, a patient with hypertension, provided 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.’

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 was not surprising that the nurse–patient relationship and therefore the relationship between the patient and the health care system was characterized by patriarchy rather than egalitarianism. Another patient, Ronelle spoke of the long time she spent waiting to be attended to. She stated: ‘I get here at 7.30am and I only leave at noon. That’s how long I sit here.’

For many patients a sense of disempowerment often accompanied having to wait for services, as they had no alternative but to comply. The fact that patients had few options but to wait their turn may have fostered a sense of alienation with regard to the public health care system. Thus, not only did patients experience the health care system as authoritarian and patriarchal, they also did not feel they had any recourse when the quality of the treatment they received was substandard.

## 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, Belinda spoke of her concern about collapsing unexpectedly. She 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. My boss, she always tells me I must rest.

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, Ella also disclosed her concerns about what might happen if she did not follow instructions from the nurse. She stated:

> 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 appeared 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 appeared to be highly salient in the narratives of respondents. In this vein, changes to diet had important implications for family functioning, especially when it came to mealtimes. For example, Maria 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 utilizing the public health system, was the reality of scarce financial resources. While most medication is provided free of charge to patients, other costs associated with travelling to the medical clinic were sometimes prohibitive.

Speaking about the tightness of her budget, Bella, a 59-year-old woman 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 their 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, Doria, a 59-year-old woman who spoke about her concerns regarding remuneration for work, 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?'

All medication was provided free of charge to patients. However, when clinics ran out of supplies of medicine, patients were given the option of returning at a later time to collect their medication, or purchasing it from a private pharmacy. For those who chose the latter option, the cost of medication was prohibitive. One respondent, Katie, expressed concern about the fact that she was unable to afford to purchase her medication. She 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.'

In addition to the costs associated with medication and clinic visits, adhering to a special diet for diabetes patients was very difficult financially. One patient with diabetes spoke of her difficulty in following the diet prescribed to her. She 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 were not trivial because for many patients they were likely to undermine seriously 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 optimizing medical compliance. For example, Analie, 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, Louise, a 70-year-old patient indicated that she had to travel a long distance to receive treatment. She stated: 'I have to walk to the clinic from where I live, which is far.'

In such situations considerable personal effort was required in order for a 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 despite the acknowledged need for treatment.

## Social support

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

> 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 was not indicated that the conversation between the patient and the nursing sister was related to adherence, it was 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 have been directly important to enhance the likelihood of adherence. Petra, a 46-year-old woman with diabetes spoke appreciatively of her relationship with her neighbour. She 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.'

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.

The question of diet was also related to social networks, as eating together could be a concern for some patients. Social networks appeared to be integral to the creation of environmental conditions for proper adherence to dietary recommendations. An environment in which the family as a whole created conditions to optimize adherence was likely to be more beneficial to patients than one in which the patient had to adhere to a diet alone. For the following participant, a diet in keeping with the requirements for hypertension had not been integrated into her family practices. She stated:

> 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 let's say dish a plate of food for them, I will dish a smaller plate for myself.

On the other hand, several patients told of instances in which family members played an important role in helping them adhere to treatment. Ronelle spoke with gratitude of the role her children played in helping her maintain a proper diet. She stated: 'They (my children) help me, yes. They tell me when I eat the wrong food.'

When asked specifically about the role her family played in helping her with her hypertension, Ronelle, a 52-year-old woman, was somewhat more equivocal. She 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.'

This respondent appeared not to want to tell her family specific information about her illness. Such reluctance may have been related to wanting to protect family members from this knowledge, or may have been due to a difficult relationship between the patient and her family. In any event, disclosing to family members the specifics of the illness may be associated with high treatment adherence.

## 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 spoke of her trouble in remembering to take her medication. She 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 expressed concern that their medication might be addictive, which was a reason that caution needed to be exercised regarding total adherence. One participant 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 South African communities. Thus, participants' reluctance to take their medication as prescribed may have been seen in terms of the stresses undergone by their communities that were characteristic of social and cultural marginalization.

Besides forgetfulness and the absence of symptoms, certain physiological reactions were associated with taking medication. One respondent spoke of his concern about frequent urination. He 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 was 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. Table 2 presents a summary of the above data.

## Discussion

The data presented in this article are among the first that focus on the contextual issues surrounding the question of adherence in the South African primary

*Table 2.* Summary of emergent themes

| *Theme* | *Examples* |
|---|---|
| Attribution of origin of illness | Onset after pregnancy<br>Onset due to psychological state |
| Experience of illness | Resigned acceptance to illness<br>Physical pain associated with illness |
| Experiences with public health care system | Admonishment from clinic staff<br>Dissatisfaction due to not being properly examined and attended to by clinic staff<br>Experience of being infantilized by clinic staff<br>Long waiting periods at the clinic |
| Concerns about the consequences of poor adherence | Fear of stroke due to hypertension<br>Headaches and pressure in the head<br>Difficulty in negotiating social aspects of eating such as family meal times |
| Financial problems affecting adherence | Cost of transport to the clinic<br>Missing a day's wages due to clinic visit<br>Cost of clinic fees<br>Cost of food required for diet |
| Transport problems | Long travelling distance<br>Absence of public transport |
| Psychosocial support | Social support from nursing staff<br>Practical support from neighbours and friends<br>Practical support from employer<br>Encouragement from family and spouse around diet |
| Understanding reasons for poor adherence | Forgetfulness<br>Absence of symptoms<br>Concern about dependence on medication<br>Side-effects of medication |

health care system in an historically marginalized semi-rural community. 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 obeys and executes those orders. Non-adherence potentially marks a patient's '"misbehaviour" as being outside the boundaries of a physician's responsibility' (Trostle, 1988, p. 1305). By conceptualizing patients as misbehaving, a rationale develops for them to be scolded or considered to be 'naughty', as was true for Maria and Ella 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. First, a patient may disagree with the clinical advice of his or her provider. For Ronelle, such a sentiment was expressed by her statement that her treatment was not explained to her but simply prescribed. 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.

Second, 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 and familial opposition to therapy. These social realities may therefore eclipse 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 in which they lived was poor. 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.

Third, clinical non-adherence may be an expression of the patients' rejection of medical intervention altogether. This rejection was likely to be true for the participant who indicated that she was reluctant to take her pills because she likened it to a habit-forming 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 expressed 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 when patients' adherence levels decrease as the physical symptoms associated with their illness diminish (Turk et al., 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.

## 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. Nicholas and Gobble (1991) define worldview as a frame of reference from which one perceives the world and a method of organizing and ordering information about the nature of events. 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 categorized and classified according to the way in which they are similar. In terms of health individuals are conceptualized as being either sick or healthy, or afflicted with a disease or not afflicted with it (Nicholas & 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. 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 conceptualization 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 to 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 contextualist worldview has the historic event as its root metaphor and is premised on relational thinking. Contextualism challenges the notion that reality is fundamentally external and stable and that human thought is separable from meaning and action (Mahoney & Lyddon, 1988). Thus the meaning of an event is embedded in its specific context, which in itself is in a state of flux and 'what is known cannot be separated from the knower' (Lyddon, 1989, p. 443). Health, illness and adherence are thus to be understood as phenomena embedded in the context of a history of social marginalization, economic impoverishment and political oppression.

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 (1979) 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, Belinda's attribution of the consequences of poor adherence included stroke or falling over on the side of the road suggests a mechanistic worldview. Similarly, Ella 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 conceptualize 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 equilibrium. The assumption therefore is that behaviour and health are systemically linked within the historical and social context of social disadvantage and marginalization in which patients find themselves. It then follows that adherent behaviour, as it may be operationalized 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 well-being (Kagee & Dixon, 2000).

## *Social support*

Social support refers to the 'information, clarification, assistance, and reassurance that an individual receives from others' (Friedman, 2002, 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 and Umberson (1988) concluded that the risk of mortality is higher among individuals with fewer supportive contacts. Similarly, a review by Hogan, Linden and 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 (for instance 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 (House, 1981).

With regard to adherence, Caplan, Robinson, French, Caldwell and 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. Ronelle'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, Petra's experience with her neighbour helped her benefit from both tangible and emotional support, while Belinda'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, 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.

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 optimizing 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 organizations (Campbell, 2003). Communities that have high levels of social capital are characterized 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 appeared to have strong positive interpersonal relationships. An analysis of the relationship between social capital and treatment adherence is beyond the scope of this article. On the whole however, the combined role of legalized racism, poverty and their concomitant social problems are likely to play an important role in influencing social capital, the sense of control people have over the course of their lives and, in turn, adherence to medical treatment.

## *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 characterized 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 organized 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 they worked, combined with long travelling distances, created unique difficulties that necessarily require conceptualizing 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.

### *Implications of the study for intervention research*

Various factors are likely to enhance the likelihood of an intervention being adopted at the individual level. Greenhalgh, Robert, MacFarlane, Bate and Kyriakidou (2004) suggest that if individuals are motivated to use an innovation, if they find meaning in it, if they have a say in the decision to adopt it, and if they have enough information about the intervention at different stages of its implementation, the intervention is likely to be adopted. Thus providing correct information about the relationship between hypertension and pregnancy, emotional expression and genetics, dispelling myths about how the illness develops, providing social support including mentoring and generally helping people accept their illness may result in positive adherence outcomes. For the uptake of interventions such as these to occur, however, support mechanisms when they are made available to patients need to meet the criteria specified by Greenhalgh et al. (2004).

Greenhalgh et al. (2004) also argue that service organizations will have a greater likelihood of adopting an intervention if the intervention has a clear and direct benefit in terms of its effectiveness or cost–benefit to the organization, if it is compatible with the organization's norms, if it is simple to use, if organizations can experiment with it at the level of application, if the benefits are easily observable, if they can be refined, if the level of risk associated with the intervention is low, if it improves performance, and if the knowledge required to use the intervention can be transferred from one context to another. Interventions that include these guidelines and that aim to alter the time-urgent nature of doctor–patient appointments, reduce long waiting periods and provide dietetic services to help identify and encourage the consumption of low-cost but appropriate food may result in the organizational culture of clinics adapting to enhance the likelihood of greater patient adherence. Similarly, mentoring and social support programming, which appear to be deficits experienced by members of the sample, may well result in positive adherence outcomes.

The question of altering the communication style of hospital staff is a more difficult concern. To be sure, the onus to engage with patients in a respectful and courteous manner rests with individual staff members. At the same time, however, the pressures experienced by clinic staff in the context of suboptimal provider-to-patient ratios and meagre material resources create conditions in which stress and burnout among clinic staff occur easily. In such circumstances the communication style of these workers may be detrimental to good patient–provider relationships. Interventions directed at enhancing communication skills need to be considered within this context. The creation of appropriate channels to address the conditions of employment of health care workers is a further imperative that may emerge from this recommendation.

At the social level, the creation of a health-promoting environment is an imperative to enhance adherence. While the question of amassing and deploying social capital lies beyond the scope of this article, this is an underlying aspect of the dynamic of empowering patients to assume responsibility for the maintenance of their health and wellbeing. The concerns expressed by participants that were associated with the availability of affordable healthy food and medication and the development of an effective transport infrastructure speak to the economic structure within which poor communities are located. The question of economic development and sustainability lie at the core of social capital and require efforts at the macro-social level.

## 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. 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 personal realities of persons with chronic illnesses attending primary care clinics.

## Limitations of the study

This study represents one of the first attempts to collect data systematically on treatment adherence from a semi-rural sample living with chronic illnesses attending primary health clinics in the Western Cape. The small sample size does not permit generalizability 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.

## Significance and future directions

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 maximize the effectiveness of health interventions, thus contributing to patients' well-being and quality of life and maximizing optimal usage of the already overburdened South African health care system.

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