A DESCRIPTIVE STUDY EXPLORING COMMUNITY- AND CLINIC-BASED TUBERCULOSIS TREATMENTS IN TWO WESTERN CAPE COMMUNITIES

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ABSTRACT

This descriptive study focused on two clinics in the Western Cape's South Peninsula (Retreat and Ocean View), with relatively successful cure rates. These successes were explored within the ecological frameworks of comprehensive primary health care (PHC) and the Healthy Cities concept. Clinic-based and community-based anti-tuberculosis treatments were compared in both areas. The relative influence of the Healthy Cities pilot project in Ocean View was also explored.

A total of 62 participants were interviewed. A semi-structured questionnaire was used for the tuberculosis patient interviews, while the other role players were interviewed using open-ended questions. Participants were selected according to their organisational role and according to their age, gender, treatment option, and pulmonary TB status.

The qualitative data was content analysed according to the three PHC principles of equity, community participation, and comprehensive approach to health care, and according to themes of health care management, the tuberculosis patients' environment and their perceptions of the disease.

Factors that contributed to the successful cure rates were ascribed to the South Peninsula's simplified approach to fighting TB, the clinic's hard work, and the recognition for their dedication. In addition, the good collaboration with the community-based project in Retreat, and the supportive clinic staff team work in Ocean View, allowed both TB nurses to ensure such successful clinic supervision.

TB patients who considered their own health as a high priority and who had good relationships with their service provider seemed more likely to adhere to their treatment. The findings further suggest that the TB patients' environments were impacting negatively on their health, making them vulnerable to first time and recurring tuberculosis infections. The curative approach taken by the clinics was successfully managing the TB crisis. It did not, however, address the underlying causes of this disease.

The Retreat and Ocean View clinics appeared not to be meeting the comprehensive primary health care measures and the Healthy Cities principles. For the clinic-based treatments, the community participation seemed insufficient to encourage the community to take ownership and responsibility for their own health. The community treatment supporters practiced a more developmental understanding of community participation.

At both clinics the accessibility, affordability and availability of the anti-tuberculosis treatment was good, however, neither clinic nor community treatments addressed the underlying causes of inequality.

The Healthy Cities pilot project faced many challenges including poor community participation, a limited budget, and little cooperation from other government departments. Despite its limited progress, it offered both clinics and treatment supporters an opportunity to expand their services to include a wider, more holistic approach to fighting tuberculosis.

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Introduction

1. Tuberculosis and Adherence

South Africa has been categorised in 1998 by the World Health Organisation as one of 16 countries hampering global efforts to control tuberculosis. The historical neglect of the TB epidemic caused by a fragmented health service of the apartheid system has left a legacy of high incidence rates. TB has become linked to specific population groups. The population most affected by the disease – according to the incidence of tuberculosis in 1990 (notification rate/100 000) - appeared to be the Coloured population group (with 599, 7 cases), followed by Africans (183,4), Asians (59,2), and finally the white population (16,5) (v. Rensburg et al., 1992; Dick, Van der Walt & Hoogendoom,1996). It is the coloured group that has been targeted for study in this thesis.

Even though the tuberculosis control programme has now been fully integrated into primary health care, and decentralised to district level, full coverage is still hampered by competing health priorities, ongoing restructuring of the health services, the slow implementation of district-level reforms, and limited management capacity at district and local levels (MRC, 2000).

The Western Cape incidence rate was, until recently, the highest in South Africa, with 32% of South African TB patients living here. The TB incidence seems to be

shifting away slightly from the Western Cape to Eastern and Northern Cape. Some suggest that this may be due to the improved implementation of the DOTS strategy, as well as more effective case finding methods (Fourie, 2001). Others believe that this change may also be related to the joint HIV and TB epidemic facing South Africa (Kleinschmidt, 1999; MRC, 2000). In 2000 it was estimated that 273 365 new tuberculosis cases could be recorded, of which 113 945 would be infectious and 46,7 % HIV positive. The HIV epidemic is rapidly unfolding, with 1 in 7 new HIV infections in Africa in 1999 happening in South Africa. The MRC estimates that in 10 years time the prevalence of HIV will be double – from 1,7 million cases to 3,5 million (MRC, 2000).

The tuberculosis rates have already doubled in most provinces over the last 5 years. If current trends continue, they are expected to increase fivefold. This would mean that by 2005 the annual caseload would be in excess of 600 000, of which 400 000 cases could be directly attributable to HIV infection, since HIV positive people are 30 times more likely to contract TB. Those infected with HIV also experience greater side effects and more than 80% of these patients die prematurely. Poor adherence rates increase the probability of MDR TB (mullti-drug resistant strain of TB), adding to the seriousness of the situation. MDR-TB is at least 100 times more expensive to cure than non-MDR TB (MRC, 2000;Williams, 1998; TB Care Committee, 1997; v. Rensburg et al., 1992).

Despite the interaction of HIV and TB epidemics in South Africa, the health sector continues to address each health issue separately (Blumberg & Constantinon, 1997; MRC, 2000; Kleinschmidt, 1999). These figures highlight the need to use available resources more efficiently to control tuberculosis and HIV, particularly with the use of, for example, community health workers.

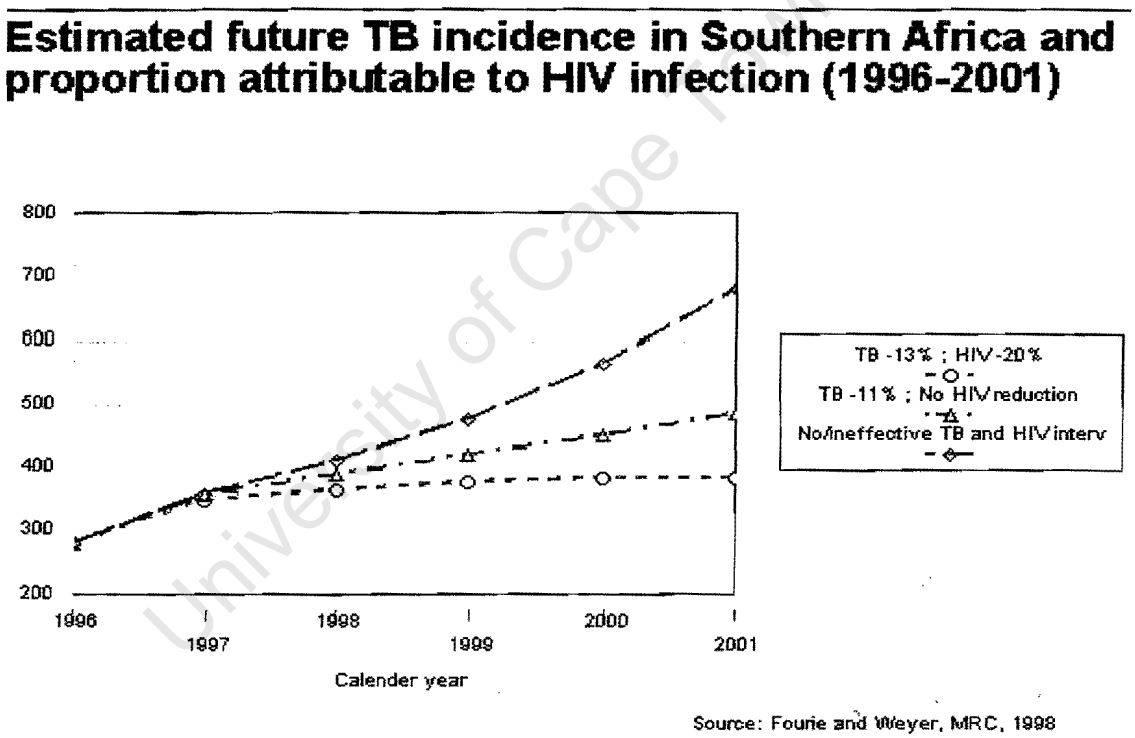

Figure 1: Estimated TB incidence in Southern Africa (1996-2001)

The DOTS strategy is the current internationally accepted best practice in the control of tuberculosis. 'DOTS' stands for Directly Observed, Treatment, Short-Course. In 1996 South Africa's TB policy was revised, based on the 5 policy issues of DOTS:

- Political commitment[1]
- Case detection through sputum smear microscopy examination of tuberculosis suspects
- Directly observed, standardised, short-course chemotherapy to all smear positive tuberculosis cases under proper management conditions
- Regular, uninterrupted, high quality supplies of all necessary anti-tuberculosis medication
- Monitoring systems involving patient registration, follow-up, and outcome evaluation enabling proper programme supervision (Nunn, 2001; Enarson, 2001)

The WHO target for TB control programmes is to achieve an 85% cure rate of sputum positive patients. Nationally South Africa's cure rate this year, however, stands at 57% and at 73% for successfully treated patients (Dick, Mbwenu & Matji, 1999; Dick, 2001).

[1] Political commitment implies that government declares the control of tuberculosis a priority and allocates a specific budget to it. National guidelines need to be published and a sector wide approach used which also ensures accessibility. Furthermore an appropriate management structure needs to be in place.

An important element of DOTS in the control of TB, is compliance: ensuring that every individual with the disease completes the prescribed course of anti-tuberculosis therapy. It aims to limit the transmission of TB by reducing the infectious period, as well as preventing drug resistance.

Compliance is generally defined as *"the extent to which a person's behaviour (in terms of taking medicine, following diets, or executing lifestyle changes) coincides with medical/health advice"* (Conrad, 1985). Non-compliance seems to be higher under certain circumstances: *"when medical regimens are more complex, with asymptomatic disorders, when the treatment period lasts for a longer time, and when there are some troublesome side effects – all of which apply to the anti-tuberculosis treatment."* (Dick et al., 1996). The magnitude of the problem of non-adherence is difficult to determine. It is estimated that roughly 40% of notified patients discontinue their treatment regimen prematurely. A third of the patients currently being treated have had TB before. Compliance is, therefore, a major problem in controlling tuberculosis (Dick et al., 1996).

2. Previous studies: tuberculosis and adherence

Several studies focusing on treatment adherence of tuberculosis have been conducted in South Africa, as well as in other developing countries. The

traditional approach has been to delineate different internal and external factors that influence compliant behaviour.

A dominant perspective locates the source of the problem of compliance with the doctor-patient relationship. Higher adherence is associated with the physician giving clear instructions and information, as well as empathetic understanding and support (Morisky, Malotte, Davidson, Rigler, Sugland & Langer, 1990; Barnhoorn & Adriaanse, 1992; Dick et.al, 1996; Squier, 1990).

Another factor which may affect adherence, is poor service. Yeats (1986) emphasised the lack of communication, motivation, and low morale of the health personnel in rural clinics in South Africa to lead to overall inefficient co-ordination and administration, which in turn affected the patients' treatment.

Another popular approach emphasises the patient's beliefs. According to the Health Belief Model, clients are more likely to be compliant when they feel susceptible to the illness, believe the illness has potentially serious consequences for their health or daily functioning, and when they do not anticipate major obstacles (e.g. side effects, costs) (Dick et al., 1996; Barnhoorn & Adriaanse, 1992; Conrad, 1985).

The importance of understanding the illness and the treatment was also found to lead to greater compliance (Liefooghe, Michiels, Habib, Moran& DeMuynck,

1995; Barnhoorn & Adriaanse, 1992; Thomson & Myrdal, 1986; Metcalf, Bradshaw & Stindt, 1990). Attitudes towards TB and its social stigma proved to be a major stumbling block in Pakistan (Liefooghe et al., 1995), in Vietnam (Johansson, Diwan, Huong & Ahlberg, 1996), the Philippines (Nichter, 1994), and in South Africa (Dick et al., 1996). TB is seen as a "dirty" disease, which affects only the poor. There are misconceptions about the transmission of the disease in the Cape Town area, which could lead to the social isolation of TB patients. The stigma results in a delay in seeking treatment or in a failure to complete the regimen (Metcalf et al., 1990). This stigma has become even more alienating because of the high occurrence of HIV positive infection with TB.

Other researchers have focused on personality factors of compliant/noncompliant clients. An active rather than a fatalistic attitude, as well as an acceptance of the diagnosis are believed to increase adherence. (Barnhoorn & Adriaanse, 1992).

Demographic characteristics of the client and socio-cultural factors have been identified as important in adherence. Mechanic's study (1992) found that schooling, income, and occupational status influence health outcomes. Thomson and Myrdal (1986) have shown that the TB policy should pay more attention to socio-economic factors. Problems of accessibility and extra cost have been underestimated. In the United States, homelessness and alcoholism were significant in predicting non-compliance (Fullimore, Young, Panzer & Muskin, 1993).

The emphasis of these approaches is on identifying independent variables (direct or indirect), which influence health behaviour. The fundamental notion is that by grouping factors, it will be possible to design effective interventions. However, problematic assumptions about the nature and source of compliant behaviour, as well as about health behaviours in general, are being made (Bishop, 1991; Conrad, 1985).

3. Problematic assumptions

Compliance is generally understood within the medical framework and is considered to be about how and why people follow or deviate from doctors' orders. Health issues should, however, be understood within the broader political and economic forces. Compliance is value-laden. The implication is that patients should comply / obey and have little option but to do so. However, clients are active agents in their treatments, having their own ideas about taking medication. There is a tendency to assume that any failure to comply is the fault of the patient. However, the patient evaluates the treatment's effectiveness and the decision to stop taking the medicine should be seen as a method of asserting control. It is important to examine the meaning the treatment as it is manifested in everyday lives (Wright & Morgan, 1990; Donovan & Blake, 1992; Conrad, 1985).

Compliance also needs to be recognised within the context of the patients' lives. The medical model assumes that all patients have free choice about their health behaviour. Some of these choices are, however, dependent on environmental influences (Coulson et al., 1998).

Many previous studies have isolated one causal factor for non-compliant behaviour, with the assumption that health behaviour is viewed as an outcome variable determined by conceptually distinct causal factors. Health behaviours, however, are a product of dynamic interaction of multiple factors, which are seen as existing on multiple levels and as having reciprocal relationships (Bishop, 1991). This means that the findings of previous research on adherence should be seen as part of a larger multiple level system that aims to contextualise non-compliance and moves beyond focussing on the individual's behaviour.

4. Tuberculosis: a social disease

Despite major advances in TB research – with the BCG vaccine and widespread use of DOTS - tuberculosis remains the leading infectious cause of death. It would seem that medicine and science have failed to curb the spread of the disease. In the 1980's the focus of health promotion has been on individuals, encouraging them to change their behaviour and lifestyle in ways that would be more likely to leave them healthy. A vast amount of research has focused on trying to understand and improve patients' adherence to anti-tuberculosis

treatment. Various studies attempt to pinpoint the predictors of compliance. Neither the knowledge nor beliefs about the cause of disease, nor personality traits or occupation seem to be predictors for adherence. Even cultural beliefs, which may play a role, can be overcome (Edington, 1997).

However, as the famous microbiologist, Rene Dubos, wrote in the 1940's, *"tuberculosis is a social disease and presents problems that transcend conventional medical approach. Its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which the tubercle bacilli cause damage to the human body."(*Edington, 1997).

The health status of households and communities is affected by the nutritional value of the food they eat, the safety of their drinking water, the purchase and use of pharmaceuticals, habitual self-care practices and by visits to traditional and providers of modern health care. Other factors such as income level, education level, employment status, genetic inheritance, quality of housing, working environment, neighborhood, social environment, quality of physical and psychological environment - all interact determining the available options and eventually the households' health status (Edington, 1997; World Bank, 1995).

The World Health Organisation defines health as a *"state of complete physical, social, and mental well being, and not merely the absence of disease or*

infirmity." Health is seen as a resource for everyday living and not the objective of living. It is a positive concept, which emphasises social and personal resources and physical capabilities. Many health professionals, however, admit that in practice this positive aspect is neglected, with the focus generally still being towards prevention of ill-health, instead of promoting existing positive resources. The WHO definition has been criticised widely as being misleading in implying that health is an *absolute* concept. As Downie and collegues (1997) argue, health is relative: health promotion and health care must help people to *better* health rather than seeking to attain a specified *level* of health.

To move toward this state of well being, people need to change or cope with the environment in which they live. Increasing the capacity of people to influence their future is the focus of development. With greater capacity to choose and respond to change people are more likely to cope with their environment. Health is therefore inextricably linked to development (Edington, 1997; Seager, 1999; Coulson et al., 1998).

The ecological perspective recognises the multiple and interrelated origins of health problems and the need for development. People who have one major problem, are more likely than others to have additional problems, resulting in a snowballing effect. For example, disadvantaged groups are more likely to be socially marginalised in more than one way. (Milio, in Badura & Kickbush, 1991).

This approach also calls for the shift away from disease specific treatments to integrated treatment systems – such as joint action to address the HIV and tuberculosis epidemics in South Africa. Health problems are interrelated as well and should not be addressed independently. Such a service would acknowledge a family's living conditions and treat the possible health threats of that environment. For example, a family living in a shack is likely to have no access to running water or sufficient sanitation, suffer from a worm infection, which weakens their immune system, and increases their chances of TB infection or slow down their recovery. Disease specific interventions are limited because they do not empower the individual or households with knowledge and practical support needed to reduce suffering, illness and mortality, resulting from various health threats (Collquhoun, 1996).

The ecological framework emphasises that neither health nor social experience can be understood apart from the other and the importance of the context in determining behaviour, such as compliance. Studies have found that adherence in TB clients is most consistently related to economic factors. These include low income, poor housing, low education level, and lack of resources. Tuberculosis research within the context of community health approach, has taken the social environment of patients into account– including living arrangements, belief systems, economic conditions, the nature of community services, and political factors. Findings suggest that compliance is generally *secondary* to a person's

overall goal to upgrade life. The disease is but *one of many* concerns for especially poor patients. As Mary Edginton, Dept of Community Health, University of Witwatersrand (1997) comments: *"Throughout the world, those least likely to comply are those least able to comply."* (Mechanic, 1992; Mydral, 1986; Fullimore et al.,1993; Ellis, 1997).

5. Health and Environments

Failing to recognise that illness cannot exist within a social, political, and economic vacuum, health workers are simply sending tuberculosis patients back to the conditions from which they came that gave rise to the sickness and non-compliance, and which may end up in chronic illness (Ellis, 1997; Milio in Badura & Kickbush, 1991).

As mentioned above, it would be simplistic to attach a single cause to disease, since complex multiple systems are involved - such as genetics, health life-history, health care service, and social context.

The environment is, however, very important in determining the health status of a population. There is a new understanding of social health issues, including factors such as violence, inadequate housing, sanitation and unsafe water, and malnutrition. It represents a move away from the medical and individual explanation of health to preventative and social explanations. It would seem that

development and a change to the environmental factors would be the most logical approach to improving health (Beaglehole & Bonita, 1997; Milio in Badura & Kickbush, 1991; World Bank, 1997).

A basic level of wealth – sufficient enough to supply essential needs such as food, shelter, clothing, and warmth - is necessary for the health of a person. Poverty is defined by the World Bank as *"a condition of life so limited by malnutrition, literacy, disease, squalid surroundings, high infant mortality, low life expectancy as beneath any reasonable definition of human decency."* Absolute poverty is defined as an annual per capita of 450 US dollars. An estimated 1,3 million people live in absolute poverty, over 70% of which are women. Another 2 million people have incomes sufficient to meet more than the most basic needs. The number of people living in absolute poverty is increasing, especially in sub-Saharan Africa and South Asia. In 1990 the World Bank estimated that almost half of the populations of sub-Saharan Africa and South
Asia live below the poverty line (Beaglehole & Bonita, 1997).

The World Health Organisation has defined poverty as *"the greatest killer"*. It can affect health directly - and indirectly through psychological processes. Wilkinson (1996) has shown how effects of poverty are mediated through low social cohesion, marginalisation of the poor and a lack of social participation. He suggests that serious health problems among poorer communities are not only the result of a lack of clean water, decent house, sanitation and basic services,

but also from the resulting feelings of despair, anger, fear, worry about income, housing insecurity, feelings of failure, and social alienation (Wilkinson, 1996).

According to the findings of the Census in 1996, 26% of the employed people in South Africa were earning less than R 500 or less per month at the time of the census. 30% of the employed population worked in elementary occupations, such as domestic work and street-sweeping (Orkin, 1997).

Health does not result directly from wealth. Once a country reaches the per capita of more than 5000 US dollars, the health standards depend on the distribution of income and the effectiveness of the public policies, such as expenditures on health personnel and health facilities, as well as literacy, nutrition, transportation and communications. Poor countries, such as Cuba and China, have achieved high standards of health, by emphasising female autonomy, literacy and political will to prioritise health, particularly for children and women (Beaglehole & Bonitsa, 1997).

More educated women marry and start having children later and also make better use of the health services and the information offered. One of the most important influences on a child survival is the level of the mother's education (World Bank, 1994). According to Census 1996, 19% of South Africans

aged 20 years or more have never attended school, while only 6% had post-school qualifications (Orkin, 1997).

The findings of the census held in 1996 further revealed that poor living conditions were characteristic of a vast majority of the approximately 9 million South African households. About 1 in every 6 (18%) households were living in traditional dwellings, and another 1 in every 6 (17%) were living in shacks.

In the rural areas and in the urban slums there is a lack of safe water and adequate sanitation, resulting in diarrhaeal disease and worm infection. It has been found that these worms lower the person's immune system, making them more susceptible to other infections, such as tuberculosis (Beyer, 2000). Just under half of all South African households (45%) had a tap inside the dwelling (Orkin, 1997).

For lighting, electricity was available to 58% of households, while 29% were still living with candles and 13% paraffin. For cooking, 23% of households were using wood, another 22% were using paraffin, and 3% were using coal (Orkin, 1997).

The South African government is struggling to provide basic services and housing for all. The RDP houses that have sprung up in the first phases of the

housing delivery are of poor quality and do not offer residents the necessary infrastructure to allow the establishment of a healthy neighbourhood. Some of these houses will only increase the incidence of TB: they have poor ventilation, are too small, and are constructed in unsuitable areas (for example damp).

While South Africa, like other developing countries, has scarce resources and widespread poverty, infectious diseases continue to be major causes of ill health. The high rates of urbanisation, parallelled with rapid, uncontrolled industrialisation, are generally unmet with sufficient environmental health services. Air pollution, pesticides, and toxic chemicals cause damage to the biophysical and ecological environment and reduce resistance to infection. Our population is also increasingly becoming susceptible to lifestyle diseases due to unhealthy work patterns, fast foods, and alcohol and cigarettes. This "double burden of disease" not only affects the health of the population, but also makes huge demands on health services, resources and the capacity of the fragile environment (Coulson et al., 1998).

Alcohol is still the dominant substance of abuse in South Africa's metropolitan areas and has a major impact on individuals and society – especially related to incidences of violence and traffic-related trauma. The increased abuse of cocaine, heroine and mandrax is a growing concern. There is an urgent need to

address the lack of treatment services available to people living in the traditionally African and coloured residential areas (Seager, 1999). Alcohol and drug abuse not only weakens the immune system, making the person more likely to contract and fall ill with tuberculosis but is also one of the major causes of non-compliance (Dick, 2001; WHO/CDC/USAID, 1998).

Violence is a major contibutor to premature death, disability, and injury. The World Health Organisation estimated in 1996 that in 1990, 1 in every 12 years of healthy life lost throughout the world was due to violence. By 2020 this is estimated to rise to one in every eight years of healthy life lost. These are mainly due to war-related injuries and interpersonal violence. Increases in interpersonal violence seem to be associated with urbanisation, rapid economic development, and overcrowding. They are enhanced by behavioural and environmental risk factors, such as drug trafficking, firearm availability, and exposure to violence of others (Butchrt & Emmett, 2000).

Even though it is not yet possible to estimate the relative burden of violence to South Africa's overall disease burden, data showed that in 1999 homicide accounted for 47,1% and suicide for 8% of all injury-related deaths on the injury surveillance system. Deaths due to transport accidents accounted for 25% of all deaths. For non-fatal injuries, violence accounted for the majority of cases in

state hospitals in 1999 – ranging from 40-70%. Only in the Northern Province were traffic-related injuries higher (Butchart & Emmett, 2000).

Violence has now been recognised as a threat to a community's health, as well as to its social order. Often, health personnel see the result of violence which has not been reported to the criminal justice system. Violence inhibits economic development by discouraging foreign investment, destabilising national labour and industry, discouraging tourism, and provoking emigration. Violence fragments families and communities and disrupts education and the provision of basic health care services. Despite the serious consequences of violence, it has been described as *"one of the most neglected problems of the late 20th century"* (Butchart & Emmett, 2000). The primary health care framework suggests that the focus should shift from reacting to the problem to focusing on changing the social and environmental factors that cause violence. Preventing violence does not only imply the control and rehabilitation of offenders (Butchart & Emmett, 2000).

Considering South Africa's socio-economic context and its implied consequences, the health services are facing a daunting task. The responsibility cannot and should not lie solely with the Department of Health. To achieve health for all South Africans, a comprehensive and intersectoral approach is needed involving all levels of government, departments, voluntary, economic and community groups.

6. Enabling Environments

The importance of creating an enabling environment for health in South Africa is increasingly recognised as not only important for good health, but as essential to human welfare and social and economic development.

Enabling environments should encourage healthy living and working conditions, which are stimulating, satisfying and enjoyable and protect the natural environment. Healthy choices are made easier and social responsibility is encouraged. These environments are made up of communities, who are able to set priorities, make decisions, plan strategies and implement them to achieve better health. Through personal and social development, available options for community members are increased and they are able to exercise more control over their lives. Within these enabling environments, health services have moved beyond the curative and clinical services, embrace health promotion, recognise the environmental and social causes of ill health, and offer holistic treatment (Coulson et al., 1998; Dennill et al., 1995).

McKeown (1976 in Dennill, 1995) showed that diseases such as tuberculosis and measles were controlled by improving the environment rather than through medical treatment such as chemotherapy and vaccination. This macroscopic

approach recognises that people are part of a wider system – families and neighbourhoods – and emphasises the need for creating enabling environments for healthy living. The focus is on prevention rather than cure.

6.1 Primary Health Care

The *Declaration of the Alma Ata* defines primary health care as *"an approach for the provision of health care that is based on practical, scientifically sound and socially acceptable methods and techniques made universally accessible to individuals and families in the community through full participation and at the cost that the community and country can afford in the spirit of self-reliance and determination"* (Richardson, 2000). The aim of primary health care is to achieve more equitable distribution of health resources and to attain a level of health for all, allowing families to lead socially and economically productive lives (Matthews, 1992).

The service relies on professional health workers, auxillaries, community health workers and traditional practitioners, who need to work together as a team. Primary health care consists of 8 basic components:

- Promotion about prevailing health problems and methods of preventing and controlling them
- Promotion of food supply and proper nutrition
- Adequate supply of water and basic sanitation

- Maternal and child health care – including family planning and care of high risk groups
- Immunisation against the major infectious diseases
- Prevention and control of locally endemic diseases
- Appropriate treatment of common disease and injuries
- Provision of essential drugs

The comprehensive primary health care approach addresses health problems by devising interventions, corresponding to the multiple causes of ill health. It is based on three principles:

- Community participation
- Equity
- Comprehensive and intersectoral approach to the provision of services

Many debates exist around these three concepts and their meaning, which has resulted in programmes called primary health care with different results.

6.1.1 Community Participation

Community participation implies that the clinic requires and promotes maximum community self-reliance and participation in the planning,

organising, operating and controlling of the health care services. The aim is that members of the community participate and assume full responsibility for their own health and welfare, which is developed through appropriate education. This principal requires community members to participate at every stage in the primary health care system – from the assessment and setting of priorities to planning and implementation of activities (Matthews, 1992; Dennill et al., 1995).

According to Hillery (1955, in Matthews, 1992) 94 definitions exist of community participation. Not only does community participation take on various forms in practice but it also - as the other principles – exists along a continuum. It changes over time and reflects very specific contexts (culture, history, government policy, social, political, and economic structures). It grows out of a specific situation and may not be able to be transferred to another situation.

There are various approaches to community participation. The medical or institutional approach sees community health programmes as an extension of the medical services. The community wanting and using the service would be considered a sufficient level of community participation (Matthews, 1992).

The health services approach perceives community participation as the mobilisation of people by the health services to take active part in the delivery of services. Many community-based projects are based on this approach. The community health worker is seen as an extension of the health services and remains under the control of the professional health workers (Matthews, 1992).

On the other hand, the community development approach to community participation emphasises the importance of people learning to make decisions for themselves that achieve change. The focus is not on the impact of the health interventions but rather on the process.

Empowerment is defined *"as moving from personal understanding to group action, increasing the control over events that determine their lives"* (Kaseje, in 1991, in Matthews, 1992). According to some, community participation is only meaningful when they are able to determine how resources are allocated. Other forms of participation have no real power to affect an outcome and are therefore seen as no more than *"empty rituals"* (Arnstein, 1969, in Matthews, 1992; Dennill, 1995).

The consequence of this principle is that communities may not identify narrowly defined health or health services problems as priorities. Ultimate goals may have to take precedence over immediate and narrow health

objectives. Only by recognising and addressing the wide range of community problems, may wide participation develop. In practice, however, economic realities often mean that community involvement and self-reliance are limited. Furthermore, the principle implies that the health services must decentralise some of its power, by including people in planning and decision-making. Communities are, however, not homogenous or equally empowered. Stakeholders may have different goals and interests in primary health care and individual interests may have a negative impact on the process. Non-participation may indicate an active choice not to participate, indicating some conflict. Other obstacles to participation are that the professional health workers do not accept the community as active members of their team, perceiving them as a threat (Dennill et al., 1997; Matthews, 1992).

6.1.2 Equity

Equity refers to the concept that essential health care is available to all. Priority should be given to those in need and at greatest risk – the vulnerable and underprivileged of society. Equity implies that the health care services need to be accessible, affordable and available care, which is delivered in the proper manner to those who need it. Accessible also includes acceptability to

the community, continuity of health service personnel, and that quality and respect are present in the relations with the community. This implies making use of community health workers, who reside in the community they serve, are chosen by the community and understand the real health needs of their community (Matthews, 1992).

Different causes lead to inequalities, such as social and economic structures, individual behaviour and health system organisation. As a consequence of accepting the principle of equity, the health services need to be decentralised and decision making power be given to primary health care centre, as well as involve community participation. From the comprehensive primary health care perspective, equity within the socio-economic context implies that the root causes of poverty also need to be addressed. Changes to health services alone would not be sufficient (Dennill et al., 1995; Downie, et al., 1997; Matthews, 1992).

6.1.3 Comprehensive and intersectoral approach to the provision of services

The third and last principle of primary health care, *comprehensive and intersectoral approach,* implies that the provision of services is a coordinated effort of health services and other health related sectors of government – for example agriculture, housing, water, education, safety and security – and

mass media and industry. Social and economic development and health play supportive functions.

This last principle has also been under debate. Some argue that it is too idealistic to be implemented by most governments. A more realistic approach would be to identify and control priority diseases with cost-effective and efficient technology. Such vertical programmes include tuberculosis prevention and control, immunisation, and HIV/AIDS prevention and control programmes (Downie et al., 1997).

This selective approach to primary health care would ignore the second primary health care principle of community participation, reinforcing the authority of health professionals. It has also been criticised for ignoring other health issues and not taking responsibility for the underlying causes of ill health. It emphasises the curative, while the comprehensive approach includes the preventative and embraces positive health, based on holistic assumptions (Downie et al., 1997; Matthews, 1992).

What remains unclear, however, is how comprehensive the *'comprehensive and intersectoral approach'* actually should be. To what degree should primary health care improve equity, participation and take responsibility for altering major causes of ill health (Matthews, 1992)?

The World Health Organisation in 1981 required primary health care to focus on what makes and keeps the poor poor – not merely 'intersectoral collaboration'. It recognised that to achieve health for all, primary health care needs to be backed by strong political commitment to social change. This implies that health and development are closely linked. One task of a health worker is therefore to create awareness of the underlying causes of health problems and to jointly develop a plan of action (Dennill et al., 1997; Matthews, 1992).

A second implication is the restructuring of not only the health system, but also of other levels of government. This has economic consequences, since the health services need to cover the whole population and resources are spread more thinly for more activities. It requires strong political commitment from national government to provide the resources necessary for infrastructure and training (Matthews, 1992).

6.2 Primary Health Care in South Africa

6.2.1 Background

The health services in South Africa have developed in a haphazard manner. After the unification of South Africa in 1910, the provinces had control over

their own health services, resulting in a fragmented health service. During the apartheid era, legislation was introduced enforcing segregation of the health services and a separate development policy. With the homeland policy, 9 more health departments were added to the already 5 existing ones, creating an expensive and inefficient system (Dennill et al, 1997; Chapman & Rubenstein, 1998).

This resulted in significant differences in the provision of health care between black and white South Africans, rural and urban, primary and tertiary health care programmes, the homelands and South Africa. Since most black South Africans were unable to pay for the services or the transportation costs and had no health insurance, they relied heavily on the public health service (Chapman & Rubenstein, 1988).

Many black South Africans were forcibly removed to live in townships or lived in homelands. The separate development policy implied that there was little concern for the capacity of these areas to sustain the population or to develop an economic base. Frequently the government did not provide adequate housing, water, sanitation, schools, hospitals, or other public services. This was especially true for the migrant workers, who lived in single sex hostels close to mines or urban areas for most of the year (Chapman & Rubenstein, 1988).

After the repeal of the Pass Laws in 1986, there was an increase in squatter communities on the periphery of the city centres. Few had access to safe water, electricity, or sewerage and garbage disposal. Overcrowding, flies, rats, and makeshift housing resulted in increased health problems, including diarrhoea and other gastrointestinal disorders, as well as worm infestations. Combined with the prevailing poverty and lack of health education, those most in need of public health services often did not receive medical care. Diseases such as tuberculosis, cholera and measles were common – many of which could have been preventable through good immunisation programmes, improved sanitation and water supply and better nutrition (Chapman & Rubenstein, 1988).

In an attempt to lighten the financial burden of the health care services on the state, a health act was introduced in the 1970's. It clearly defined the duties, powers and responsibilities of the health authorities and encouraged the private sector to participate in a more comprehensive and accessible approach to health care (Dennill et al., 1997).

In 1986 the National government formulated the National Health Plan, which aimed to meet the health needs of all South Africans. It was based on the Alma Ata principles. By 1991 the intention of government to provide health for all was introduced with the National Health Service Delivery Plan. Within 5 years a comprehensive and affordable health service should be developed,

which would be planned according to priorities identified by communities. The transformation of the health service started – the right of admission of all population groups to public hospitals; reorganising health services to regional and local level, with local authorities taking responsibility for most primary health care services; more funds being made available to primary health care; advocating community participation; and health workers undergoing community-oriented training (Dennill et al., 1997).

6.2.2 Transformation

The Health Department has adopted the purist understanding of the primary health care principle of equity, which they hoped to implement as quickly as possible. With the introduction of free health care for pregnant women and children under the age of 6, there was a dramatic increase in clients to the clinics, who were not consulted or given the necessary resources to deal with the increased demand. Even though systems have now adjusted to a certain extent and more people have access to health care than before, the clinic staff continue to be preoccupied with the care of children, even though most cases are minor (Price, 1999).

500 clinics were identified for upgrading or new construction and financed by the RDP budget. No allocation was, however made for the operating costs.

Some clinics were staffed with people who were not trained to provide primary health care. Other clinics could not be opened at all. Nevertheless, the building programme extended the reach of primary health care into new areas, which are now being used (Price, 1999).

A further consequence of the equity principle has been the reallocation of resources. In 1994 there were huge discrepancies between the provinces' budgets, with the Northern Cape only receiving one quarter per capita of the budget than that of the Western Cape. Consequently the Western Cape was asked to make budget cuts of 30% a year. Since 60% of the budget was allocated to health personnel, the Health Department tried to reduce it by using the 'voluntary retrenchment policy'. As a result many 'good people', knowing that they could find employment elsewhere, left the public health service with a generous package, while the others stayed. In order to reduce budgets, competent managers are required. In most provinces completely new senior and middle-level administrators with little experience applied for the positions. They have had to since oversee several transformation and restructuring processes – from the inclusion of the former 'homelands' to the integration of the health services (Price, 1999).

This has resulted in poor management conditions in clinics. According to Dick (2001) one of the three main obstacles to controlling tuberculosis are

organisational issues within the health care system. As mentioned before, the restructuring of the health sector has not only resulted in the loss of key people through retrenchment, but has also created a sense of job insecurity. Managers are caught up in the restructuring and crisis management. Generally staff are demotivated, not well managed, and only task orientated, which disassociates them from their clients (Dick, 2001).

There are current efforts to decentralise not only health but also other related services. With the introduction of the Integrated Development Plan (IDP), local government is legislated to address community needs using a more integrated approach. According to this legislation, the health department should no longer work in isolation but within a team of officials from all the directorates such as housing, planning, community development, and economic development – to address health concerns. Local government structures and budgetary processes, however, need to change as well in order for the IDP to work. Directorates are generally not working together effectively (Nel, 2000).

To achieve an enabling environment for health, a strong political commitment to improving health is required, which is reflected in the preferential government spending. Health is currently still only receiving a fraction of the overall budget (Dick, 1997). This needs to be combined with an intersectoral

perspective in planning and operating systems of health care, including provisions of safe drinking water, sanitation, housing and health education. An appropriate organisational framework and managerial process, equitable distribution of health resources, and community involvement at all levels need to be in place (World Bank, 1995).

7. Healthy Cities Concept

One organisational strategy that attempts to tackle such a broad range of factors, found within eco-systemic thinking, is the World Health Organisation's Healthy Cities Project. The project was launched in 1986 in Lisbon, Portugal and has since then mushroomed into a worldwide effort with participants on every continent. The ultimate goal of the project is to improve the health of all people living or working in cities by obtaining a commitment to work for health from different sectors (Edington, 1997; World Bank, 1995; Carolissen, 2000).

"A Healthy City is one that is continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other in performing all the functions of life and in developing to their maximum potential." (WHO, 2001)

The model sees health promotion primarily as an issue for communities as a whole working together, instead of activities focusing on individuals. The main

premise of their approach is that health is seen as social rather than medical. It recognises the physical, social, mental, economic, and environmental dimensions of health. Health is believed to be achieved through the outcome of the collaboration of community members, planners and providers of all public sectors and private services. It is ultimately about more than health because every sector should be involved and no one sector should dominate (Ashton, 1992; Baum, 1996; V. Schirnding et al. 1999; Goldstein, 1999).

The overall objective of the Healthy Cities project is to tackle the underlying and structural causes of illness and disease and is based on 6 strategic priorities:

1. Reducing the inequalities in health opportunities
2. To create a physical environment that supports health
3. To create social environments that support health
4. To strengthen the communities capacity, ability, and opportunity to take action to protect and improve their health
5. To develop the skills needed to be healthy
6. To re-orientate the health services towards health promotion, disease prevention and community-based care

Through Healthy Cities other objectives, such as "health for all", environmental health, health promotion, Agenda 21, hygiene education, etc. can be put into action (Goldstein, 1999).

The city is seen as optimal for intervention, made up of neighbourhoods and communities, with a variety of people, institutions, values, and cultures. The challenge is how to create a health programme that meets these diverse needs (Ashton, 1992).

To achieve community development a partnership between people in a particular area working with professionals to identify their concerns, devise and implement strategies to address these health concerns, needs to be established. Generally, wherever a community has been involved in identifying the health issues of concern to them, they have mentioned those that are linked with living, working, and environmental conditions as being the most important to them (Ashton, 1992).

The Healthy Cities concept emphasises the settings approach, as well as the principle that health can be improved by modification of living conditions. Settings *"are major social structures that provide channels and mechanisms of influence for reaching defined populations."(WHO, 2001).* Each setting consists of a unique set of members, authorities, rules, and participating organisations. Within the setting there is frequent and sustained interaction of formal and informal communication. A city, home, school, neighbourhood, bus station, workplace are all settings in which people live and work. The condition of these settings affects the health status of the people that interact within them. These settings provide entry points to specific populations for health initiatives. For example, in a school

setting, the parents, school principal and education authorities may develop a plan to install adequate water and sanitation facilities within the school. Partnerships are then established between community groups, community-based organisations, NGOs, local institutions and district and local government agencies (WHO, 2001).

Healthy Cities brings together all the development sectors that can lead to a health transformation through creating enabling and healthy conditions in the various settings. This depends on a partnership between local government and the Healthy Cities. Local government needs to be strong and mandate accountability, transparency and participation, as well as encourage intersectoral cooperation. This partnership would allow for the development of initiatives aimed at local settings and highlighting the health dimension of different sectors' functions (WHO, 2001).

Considering that South Africa faces various health threats besides tuberculosis, and is further constrained by a rapid population growth, cultural gender inequalities, and pervasive poverty, such new approaches to create enabling environments are called for.

In 1996 a process was initiated in Cape Town to develop such a Healthy Cities project. A steering committee was established, consisting of non-governmental organisations (NGOs), community based organisations (CBOs), and a number of

sectors including health, education, and housing. A smaller core group took on tasks and formulated a proposal for a Cape Town Healthy Cities project (Carolissen, 2000).

The following recommendations were made:

- The overall aims of the project would be to improve the health and quality of life of the population by placing health on the agenda of decision makers across sectors.
- The primary focus would be on building onto and coordinating existing activities in the city including links with the communities and authorities, and between health and sustainable environmental agendas.
- The project would be based in the Cape Metropolitan Council (CMC), which has coordinating responsibilities for the Cape Town area.
- A multisectoral steering group would continue to guide the project and ensure accountability both by authorities and by communities, with a full time coordinator employed to manage the project.
- The emphasis would be on capacity building, using existing forums (Carolissen, 2000).

Following the development of the plan, one year of lobbying to various authorities started, with the aim of obtaining funding, involvement, and ownership of the project by authorities. The CMC agreed to cover the costs of the salary of a coordinator, who was appointed in 1997. The other authorities agreed to contribute a sum of money towards the pool, which would pay for capacity building and the development of 'lead projects' to illustrate the Healthy Cities approach (Carolissen, 2000).

The ability of the Healthy Cities project to influence change within local government depends largely on the extent to which the project is able to gain access to where service provision is planned. This contributes to a shift from the vertical approach to a more integrated, comprehensive primary health care approach. Integrated Working Groups (IWGs) have been established to assist with this shift. They provide a strategic site for capacity building, conceptualisation and development of current projects of local government, including aspects such as housing, water and sanitation, and local economic development (Carolissen, 2000).

Healthy Cities activities include a diesel testing project in conjunction with the CMC Air Pollution Unit, a project focusing on tyre burning, and a range of clean-up campaigns throughout the different local councils. Together with TB NGOs and the health services, the Healthy Cities project is looking at the links between tuberculosis and the environment, as well as at ways to increase community-

based tuberculosis treatment. In conjunction with the Medical Research Council, Health Promoting Schools Project, University of Western Cape Public Health Programme, and the City of Tygerberg, the Healthy Cities project is conducting a pilot project in Khayelitsha to address the worm infestations amongst school children. The focus is on de-worming, educating and on health promotion. Other initiatives the Healthy Cities project is involved in include a disabled transport project, compiling a database of NGOs, CBOs and other organisations working in areas of health and development, as well as developing social development indicators (Carolissen, 2000).

Healthy Cities was first established as a metropolitan wide group in Cape Town. The process was then taken to the local councils, who each were supposed to set up their own integrated working group, which would take the Healthy Cities concept to the communities. At the time of the study, only the South Peninsula, Helderberg and the City councils had Healthy Cities integrated working groups in place.

Ocean View was identified in 1997/8 as one pilot site where a Healthy Cities project was launched 1 ½ years ago. The area manager of the South Peninsula's Environmental Health directorate was responsible for putting this pilot in place. An integrated working group was established, consisting of senior managers of the South Peninsula municipality and three councilors.

8. Social Capital

Healthy Cities is based on the principle of community participation and assumes that it is strong and well in all communities. Participation is not only seen as "healthy" but is a prerequisite for advances in public health.

In South Africa, however, racial oppression and apartheid have resulted in social disintegration – especially in black communities. Social disintegration presents itself as a breakdown of family life, high unemployment and alcohol and drug abuse, high crime rates, despair and acceptance of the victim image, and the flight of skills and positive role models from townships to higher income areas (Butchart & Emmertt, 2000).

Findings, such as the studies on crime, have found that in areas with the highest crime, the communities are most reluctant to organise themselves for community meetings because of high levels of distrust. This was found especially so when crime was identified as coming from within the community. People were reluctant to cooperate with their neighbours. The majority isolate themselves from the community to protect themselves from crime. This is seen as one explanation for Neighbourhood Watches being less successful in poor communities (Butchart & Emmertt, 2000).

Generally poor and crime-ridden communities do not only lack financial resources, but also social resources to address their problems. Through disintegration these resources have slowly eroded. Such resources which people can draw on to solve common problems are referred to as social capital. Social capital is defines as *"those features of social life – networks, norms, and trust – that enable participants to act together more effectively to pursue shared objectives."* (Putnam, 1996, in Butchart & Emmertt, 2000).

Without this social resource, others, such as gangs, vigilantes, and warlords, are free to build up their own social capital and impose their controls, norms, and interests on the community (Butchart & Emmertt, 2000).

As inequality increases, so the quality of social capital drops, and for example violence increases and the population's health suffers. Income inequalities are strongly linked to social distrust and poor social cohesion. Butchart and Emmertt (2000) believe that social capital plays an even greater role in determining the health status of a community than poverty. One explanation is that when a community has little social capital, they are less effective in exerting any informal social control/ pressure over its members to establish norms that encourage social responsibility and healthy choices (Butchart & Emmertt, 2000).

Good governance and sustainability, as well as Healthy Cities, depend on a strong civic community (social capital), represented by effective social relations

and networks. It is also an important feature of economic development, facilitating cooperation and communication (Butchart & Emmertt, 2000).

It is clear, therefore, that the issue of social capital needs to be addressed in South Africa, especially in the poor communities, if primary health care and Healthy Cities should succeed.

9. Tuberculosis Control Programme in South Africa

9.1 Clinic- and community-based treatment

Traditionally, tuberculosis patients have only been treated at clinics under the supervision of professional health personnel. The patient receives daily treatment at the clinic, administered by a clinic nurse from a treatment room. This method of tuberculosis control has been widely criticised for the generally poor patient and health care worker interaction related to overburdened, overworked and unmotivated staff (Mahler et al., 1997; Dick 2001; Morisky, Malotte, Davidson, Rigler, Sugland & Langer, 1990; Barnhoorn & Adriaanse, 1992; Dick et.al, 1996; Squier, 1990). The clinics' overall objective is to reach the WHO target of 85% cure rate of smear positive tuberculosis patients. By using the patient-centred approach, clinic staff strive to achieve a good relationship with patients. Other responsibilities include raising awareness of TB, actively finding new TB cases and providing

TB patients with one meal a week.

Community-based supervision implies that the tuberculosis patient receives daily treatment from a trained community member (treatment supporter) who lives in the patient's neighbourhood and ensures that the patient adheres to the treatment.

This method of treatment draws on the community's resources and should relieve the workload for the clinic staff. It also aims to create a sense of responsibility and ownership for the community's health. The community treatment supporters are an important link between the clinic and the client, and seem to improve adherence. In some areas the treatment supporter is paid a small incentive. Even though this does raise the costs of providing community-based care and problems of sustainability of such projects, the incentive encourages greater accountability in attending training sessions and meetings and in ensuring adherence (Dick & Henchie, 1998; Dick et al., 1997). The Department of Health subsidises a third of the incentive, with the non-governmental organisation working within tuberculosis, such as TB Care, paying the other twenty Rand.

According to a cost analysis of treatment options in 1998, the estimated costs per patient for a six month period at the clinic costs R 3600, while self-supervision costs R 1080, and community-based treatment costs R 720 (which has not taken into account the small incentive some community treatment supporters receive). The findings imply that community-based treatments are more cost-effective than the ones based in clinics. By decentralising the provision of TB and HIV care beyond the health facilities and into the communities, resources are utilised more effectively, with the potential of addressing the limitations of the health care system in facing the joint HIV and TB epidemics (WHO/CDC/USAID, 1998).

Their success, however, depends on a combination of elements – including the cooperation and commitment of the clinic staff and health care system.

9.2 Successful TB Control Programmes

Successful interventions use multiple strategies to enhance patient adherence, including:

- Increased quality of patient education
- Improved convenience of the treatment strategy
- Providing positive reinforcement for patients (Dick, et al., 1997)

Such strategies require the willingness of all role players. Cure rates are more likely to be high when the implementation of the intervention has been as a result of a direct request from the community. The programme also should have a high level of community awareness, as well as a strong community-development aspect, with long-term objectives to improve the health of the community (Dick et al., 1997).

Findings suggest that committed and dedicated professional health workers are important with respect to the effective design and implementation of treatment programmes. Such health care workers also need to have a certain level of respect from the community, which is difficult to achieve. They should have good ongoing relations with the health care staff and the TB patient, their families, employers and community. High cure rates are also more likely when there is an *"unbroken chain of care"* (Wilkinson, 1997; Dick et al., 1997).

Close collaboration between outside organisations, such as non-governmental organisations – is vital when joint treatment approaches are being developed. Successful collaboration depends on good communication links and referral schemes, training of NGO supervisors and health service staff, as well as a system of regular monitoring of community treatment supporters (WHO/CDC/USAID, 1998).

Successful community-based projects have clearly defined limits to the lay workers' responsibilities, with clearly defined limits of practice and system of referral and support. An ongoing system of monitoring of their skills and activities, as well as continual support from the health care workers were identified as important and motivating. Community-based projects can, however, not be implemented and then left to run on their own. Sustained programmes require high levels of professional support and control. They also need to be well integrated into the formal health sector, the community-based programmes may become problematic.

9.3 TB CARE

TB CARE, a non-governmental organisation, developed a system of community-based supervision to take DOTS management of the TB patient to the community. The patient can choose the most convenient treatment option: at the workplace, the clinic, or in the community. TB Care is involved in community-based tuberculosis projects throughout the Cape Metropole.

ne overall aim of the project is to achieve the WHO target cure rate of 85% f smear positive tuberculosis clients the first time using community-based OTS. To achieve this, TB Care's objectives include:

- Making the treatment of tuberculosis accessible to the client
- Raising the awareness of tuberculosis
- Empowering the community
- Raising the tuberculosis client's sense of self-worth

is hoped that the training of community members as treatment supporters nd by offering social services to tuberculosis clients – such as nsultations or group work with a social worker and handing out of food ouchers – the above mentioned objectives will be met.

ne project is administered by 5 qualified social workers and 2 social work xiliary workers and is coordinated by the director. The administrators or ordinators are each responsible for a specific area in the Western Cape. esponsibilities can include the training of community members as eatment supporters and on other health related issues, monitoring the care TB patients by community treatment supporters, developing the treatment pporter group in administrative and fundraising capacities, communicating th the clinic managers and staff, counseling TB patients and handing out od vouchers. Another recent responsibility of TB Care coordinators

include the overseeing of treatment supporter/clinic projects, such as the garden project, as well as running of workshops with TB patients. TB Care and its coordinators are also involved in creating awareness at the workplace about TB and educating the employer about DOTS.

The director is responsible for the overall coordination of TB Care and for fundraising. TB Care's decision-making body, the TB Care Council, consists of representatives of the treatment supporters of all areas and the deputy director and the director.

TB Care works closely with the Department of Health and the Provincial TB Control Programme and is also accountable to their funders – such as Community Chest.

9.4 Introduction of community DOTS to Retreat and Ocean View

The non-governmental organisation, CHASA, approached the Health Department in 1989 to start a pilot community-based supervision programme in Retreat. The treatment supporters were seen by the department as extensions of their clinic staff and the initiative was welcomed.

The pilot ran out of funding because of unrealistic planning and incentives and was taken over by TATSA, an organisation that trains community members on HIV and TB issues. By the early 1990's TB Care finally took over the management of the community treatment supporters because TATSA concentrated only on training. From the 15 community members, who were initially trained by TATSA in Retreat, only 5 were active at the time of the study. These five women have been working as treatment supporters for the last 6-7 years.

TB Care has only been involved in Ocean View since 1999. As in Retreat, TB Care communicated with the South Peninsula municipality and with the Ocean View clinic staff. There was no introduction or contact with the local leadership in both areas. In April 2000 the treatment supporters group was launched for the first time, introducing the treatment supporters to the community. From the 7 community members trained, only 5 were active.

9.5 Roles and responsibilities of Treatment Supporters

The overall aim of treatment supporters is to lighten the workload of the nurses with the respect to TB treatment by offering community supervision. Treatment supporters are responsible for community-based DOTS, record

keeping, building and maintaining a good relationship with the TB patient, as well as raising the awareness of the community about TB and being involved in different projects. They have to collect the medication from the clinic, remind clients of doctors' appointments, and follow up on patients who have missed one dose of treatment within 24 hours. Besides their duties relating to DOTS, the treatment supporters have to attend monthly meetings and training sessions. Treatment supporters can also help out at the clinic on a voluntary basis.

Within their group, the treatment supporters are expected to raise funds through organised events and functions within their area. They are also responsible for their own bank account.

9.6 *Roles and responsibilities of TB nurses with respect to community DOTS*

The TB nurse, on the other hand, is expected to place patients with treatment supporters, pack the monthly medication in envelopes, ensure that the medication reaches the supporter, introduce the patient to their new treatment supporter, keep records of the treatment supporters and their clients, and record compliance. The TB nurse is also expected to attend and participate in the monthly treatment supporter meetings, as well as the Health Committee meetings. There should also be good communication between TB Care and the TB nurse about the treatment supporters. A

partnership should exist between treatment supporters and the TB nurse, in which both are supported.

CHAPTER TWO

History of the Research: Reflections on Practice

This study has evolved over three years, changing shape and objectives for various reasons. This chapter will explore these reasons and my experiences in order to give some insight into tuberculosis research in practice in the public health sector and in communities.

1. Initial approach

1.1 Background

Tuberculosis grabbed my attention because of the alarmingly high incidence rates in the Western Cape. After exploring the issue, I came across the unusual situation in Mannenberg. Despite their continuing gang violence and occasional forced closure of the clinic, their cure rates were surprisingly high. I hoped to explore their success and to find important components that may enhance compliance. As a comparison, I chose to also look at tuberculosis patients at the Hanover Park clinic, which is situated close to Mannenberg, with a similar population and less gang violence. While the Mannenberg clinic makes use of community-based supervision through the non-governmental organisation TB Care, the Hanover Park clinic relies on clinic supervision alone.

the objective of this study was to trace the subjective experiences of
ulosis patients over their six-month treatment period to understand
ance from the illness cognition framework.

cognition is the study of mental representations of health and of illness.
oes the individual think about and how are these concepts understood?
eoretical framework emphasises the contextual nature of people's
ses to health threats. Leventhal, Nerenz and Steele (1984) propose that
beliefs are structured and that the core consists of subjectively perceived
ms and attributions concerning their causes. This is derived from
tion presented in the social environment and from past experiences.
related behaviour is, therefore, part of an interactive process. A person
tes both internal and external stimulus information with existing cognitive
ata to give meaning to a person's experience. This meaning directs his/her
the results of which provide feedback by which the coping and the illness
ntations are evaluated and updated (Bauman, Cameron, Zimmerman &
al, 1989).

. Real

ude possible extraneous variables, I chose the following criteria: adult,
ary tuberculosis patient, who has never had TB before and who has just

recently started the treatment (within the first two weeks). The objective was to trace the patients over their six-month treatment by interviewing them every two months. This, I hoped, would allow me to record the changes in their beliefs and thoughts about their treatment and about compliance. The strict selection criteria, however, made it very difficult to find participants for the study. The Mannenberg and Hanover Park clinics treat an average of an estimated 80-90 TB patients a month. These include children, retreatment patients, patients who have already been on treatment for a while and patients with TB other than pulmonary tuberculosis. It was therefore almost impossible to find a 'correct' participant, who was also available and willing to be interviewed.

Another reason why data collection was difficult is that the research sites - especially Mannenberg – are volatile areas. They are situated on the Cape Flats, which are plagued by gang warfare, poverty, and unemployment. Mannenberg is divided into 12 gangster territories, with the clinic situated on the border of three rival gangs. While the clinic falls in the territory of the Hard Livings, the area behind the clinic belongs to the Americans and the area opposite to the clinic belongs to the Dicksie Boys!. Often the clinic is caught in the crossfire. High walls and strong security bars surround it, with a security officer in bulletproof vest and rifle standing at the clinic entrance checking patients for weapons.

The Mannenberg clinic's services have been disrupted several times, resulting in the closure of its doors to all patients. During data collection the clinic had to close three times and the staff and myself were escorted out by police and heavy security. Hanover Park is less volatile and the atmosphere in the clinic was less tense and the people less distrustful. Data collection was, however, complicated by ongoing renovations at the Hanover Park clinic, resulting in chaos and confusion.

In addition to these disruptive factors, the clinics had to deal with a nurses strike, a twister ripping through Mannenberg in 1999, resignation of the clinic manager in Mannenberg, and the other 'normal' burdens, such as understaffed and demotivated nurses and doctors. These conditions made research very difficult.

Since not all patients in Mannenberg are supervised in the clinic, and the selection criteria was limited, I would only see one or two patients per morning of which, on average, only one per week would be willing to participate. Some patients were too ill and weak to take part in the study. Others felt that they did not have the time or said that they were uncomfortable answering questions.

Patients would only come to the clinic between 8:30 and about 11:00 in the morning, Mondays to Fridays. They come, sometimes to see the doctor and for their treatment. The arrangement was that I would sit in a small room next to the

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The women were more forthcoming and helpful. None of the patients agreed to have our conversation recorded.

I had spent a lot of time at the clinic, eventually became a familiar face, and had good rapport with the nurses and the community treatment supporters. Nevertheless, I continued to be an outsider. It made me very aware of my responsibility as a researcher in creating a culture of reciprocation. After writing several fundraising letters, I managed to receive one donation from the Seven Eleven for fifty Rand, which I used to make sandwiches for the participants. I continued to give sandwiches to those participants who wanted them and donated money to the breakfast club in both clinics. I offered my help to the nurses – typing, administration – but they could not find anything appropriate for me to do without having to supervise me.

Since Afrikaans is not my mother tongue, my "otherness" was even more pronounced. I had the questionnaire translated into academic Afrikaans, only to find out that this alienated me from the participants. With the help of the TB Care Coordinator, the questionnaire was rewritten into the 'Cape Flats Afrikaans', which I hoped to be more accessible.

Generally I found that people felt comfortable speaking about their symptoms and how they were struggling with tuberculosis – as they would during a consultation with a doctor. Any questions beyond that were answered with yes/no

or one-word answers. In many cases I had a strong sense that some of the answers were not truthful. Some appeared to 'just go through the motions' so that they would be able to get on with their day and see the doctor.

To make the study less obtrusive for community-based patients - and because I did not feel safe enough to visit patients at their homes - I decided to train community treatment supporters to administer the questionnaire. This impacted on the design of the questionnaire, which had to be simple enough for the semi-literate supporters to use. I ran two workshops with the treatment supporters in the local library, explaining the illness cognition theory and working through the questionnaire, question by question and using role-play. It took several attempts to get every one together on the same day at the same time. I drew up a schedule and reminded them when they should interview whom. Since there were only a few participants I had managed to interview during the first phase of their treatment, there were not many to follow up on.

I was faced with a different problem in Hanover Park. Before long I realised that a time-series study would be complicated because the majority of patients did not have a telephone, making follow-up appointments very difficult. I relied on letters to remind patients of our appointment and hoped that they would come to the clinic for the follow-up interviews.

I had approached the non-governmental organisation, TB Care, in the beginning of the study, asking if I could study compliance through their treatment service. They were helpful and interested because they hope to use the findings of this study to advertise their agency's success.

The 'official' introduction by TB Care helped me to gain access to the Mannenberg clinic and win the clinic staff and treatment supporters' trust. Since Hanover Park does not use community-based treatment and is not working with TB Care, I requested the clinic manager's approval and cooperation.

The nurses and community treatment supporters were very helpful and made the time to speak to me. I slowly got to know them by attending the various meetings, organised events and training sessions. I ran focus groups and interviewed the treatment supporters and the TB nurses individually.

2. Change in theoretical approach

I was initially drawn to Illness Cognition framework to understand compliance and health behaviour because other health psychology frameworks did not seem to recognise the importance of social context. This context is only indirectly recognised as part of the individual's cognitive belief system. If a person does not know about the possible links between the environment and health, these contexts may be excluded from the understanding of health behaviour. Once I

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suggested Retreat and Ocean View. Both clinics have high compliance rates and use community-based and clinic supervision. I then had to apply for permission to conduct research in the then South Peninsula Municipality (SPM). Even though the City of Cape Town had granted me my request for Mannenberg and Hanover Park, the new study sites fall within the SPM jurisdiction. This proved to be a very lengthy process. I met with the Manager for Community Health of the SPM, who was very positive about my involvement and requested a proposal.

I had to rework my initial proposal. After having read more widely, I came across the World Health Organisation's Healthy Cities project. It seemed to address all the reservations I had of the Illness Cognition theory and is based on the settings and ecological approach. I changed the focus of the study to health systems, exploring the different tuberculosis treatment services against the primary health care and Healthy Cities principles. No longer would I try to trace patients' over the treatment period. I widened the selection criteria to adult pulmonary TB patients, no matter how often they have had TB or which stage of the treatment they were at. I also decreased the number of TB patients to be interviewed to a more realistic 20 respondents for each area.

I presented my proposal to my supervisor and then to the community health manager. Between the two of them I had to change my thesis proposal four more times. Concerns were raised about the validity of comparing two very different

communities, Retreat and Ocean View. However, since Ocean View was recently introduced to the Healthy Cities concept, it seemed important to include this area. It was agreed that the focus of the study was not on generalisable findings, but rather on subjective reflections, and the differences between areas would be taken into consideration. Finally, after long periods of consultation and reworking, the proposal was accepted and permission for the study was granted by the SPM (community health manager).

Besides the go ahead of the SPM, I also had to consult with the Healthy Cities Coordinator for Ocean View. Initially he did not welcome my request to do research in Ocean View. He felt that since a lot of studies were being conducted in the area, the community may end up feeling used. This, he believed, could result in a breakdown of trust and may jeapordise his attempts to set up the Healthy Cities project. After explaining the relatively small scale of my study, he granted me permission to go ahead.

3. Second Approach

New relationships had to be established with the clinic staff and community treatment supporters. Again, the introduction by the TB Care coordinator was very valuable. As in Mannenberg and Hanover Park, I sat in on several staff and

community treatment supporter meetings, attended TB Day events and observed the daily routines at the clinics and treatment supporters' homes.

I noticed that the atmosphere in the clinics was different to Mannenberg and Hanover Park. Even though the staff were just as busy, they appeared less stressed. People seemed less suspicious, even though they still greeted me as 'Sister' or 'Doctor'. This difference in power relations between the participants and myself continued to be an issue during interviews. There seems to be very little that can be done to change this dynamic. I tried addressing it by offering tea and coffee or sandwiches and joking around a bit to create a less formal setting. Due to the limitations of the facilities and the limited space it was very difficult to offer anything without taking up too much of the participants' time.

With the new selection criteria I managed to speak to more people and interviewed a sufficient number of clinic-based patients in both areas. I had more difficulty getting hold of community-based patients. One reason is that there are fewer patients receiving community supervision than clinic-based treatment. Patients in Ocean View had only until recently been given the option to receive community based treatment. What made data collection difficult in Retreat was that many patients were employed and declined participation because they felt that they had no time for my questions. This meant that the population for

community-based participants was very limited. I was also dependant on the treatment supporters' cooperation, which made data collection more time consuming and complicated. The treatment supporters acted as the link between the patient and myself. The participant was selected according to the treatment supporters' "advice". Sometimes treatment supporters did not think that the patient would have the time to speak to me or that my questions may influence the treatment process. The supporters helped set up the interview, which took place when they were going to the treatment supporters' home for DOTS.

4. Conclusion

Only through experience do students and researchers learn that theoretical research designs cannot simply be imposed onto a real setting – a notion that seems obvious. Without sufficient background knowledge of the context of the proposed study, a researcher may easily make incorrect assumptions about the most appropriate research approach. I, for example, underestimated the complex procedures and bureaucracies involved in gaining access and finally undertaking research within the public sector – specifically within the public health sector. Even though this study has taken a year longer to complete than planned, I have met many more people involved in the fight against the disease from other contexts during this time. This allowed me a greater understanding of tuberculosis and gave me the opportunity to search for a more appropriate theoretical framework that seemed to capture the complexities of the disease.

According to Colloquhoun (1996, in A. Kellerhaer & D. Colloquhoun, 1996) health research should focus on three essential components. The first is a clear understanding of the social factors at multiple levels of analysis, which affect the nature and distribution of health problems. The second is that knowledge of interventions should involve multiple levels of analysis. The third component should be an in-depth understanding of the community, organisations, neighbourhoods, networks, and the individuals who shape the context of health intervention programmes. This methodological framework also reflects the underlying understanding of the aims and objectives of the primary health care and Healthy Cities principles discussed in the first chapter.

In this study the perceptions of clients, service providers and their management are explored to provide a more complex view of the tuberculosis experience and moves away from focusing only on one factor, for example, the patient.

3. Study Design

The focus of this study is on providing insight into environment/social context, equity, community participation, and comprehensive approach to health services through the subjective experiences of role players involved in two different TB treatment services. Through qualitative research methodology -including in-depth interviews, focus groups and observations - these experiences are seen through

the eyes of the people involved in tuberculosis, as well as allowing the researcher to add another perspective.

Qualitative research methods are able to show how complex structures of meaning and situations interrelate and how a relatively small group of people understand their world. Lessons can be drawn from such qualitative data and applied to similar situations and groups of people. Qualitative research methods have been criticised for not having tried and tested methodological guidelines. Generalisability is usually uncertain and the researcher may seem more like a political activist rather than a researcher. Daly and colleagues (1996), however, argue that since public health research aims to change things for the better, it is ultimately a political act and therefore subjective. By recognising the limitations of qualitative research methodology, steps can be taken to compensate for them. Daly and colleagues (1997) suggest that the problem of validity of data can be addressed by the sensitivity of the relationship between the researcher and the researched. The reliability of analysis in qualitative studies depends on the acceptance of it by participants and public health peers.

All main role players in the treatment of tuberculosis - in the clinic and the community - have been drawn into the study to reflect a wider and more complex context within the tuberculosis treatment (See figure 2). Interviews and focus groups were conducted first with the service providers and then with the clients or patients.

Observations and existing clinic records – such as the TB Register and other health and Census statistics - were used to complement the data collected.

The two sites – Retreat and Ocean View – were selected because in both areas TB Care was involved, the clinics were reporting high and improving cure rates, and the communities were made up of similar population and income groups. Even though Retreat is larger than Ocean View - with approximately double the population and a larger client case load compared to Ocean View – the number of TB cases in Retreat is still not as high as in other areas such as Nyanga or Khayelitsha, which may affect the running of the clinics. A Healthy Cities project was also piloted in Ocean View and could be compared to an area without such intervention.

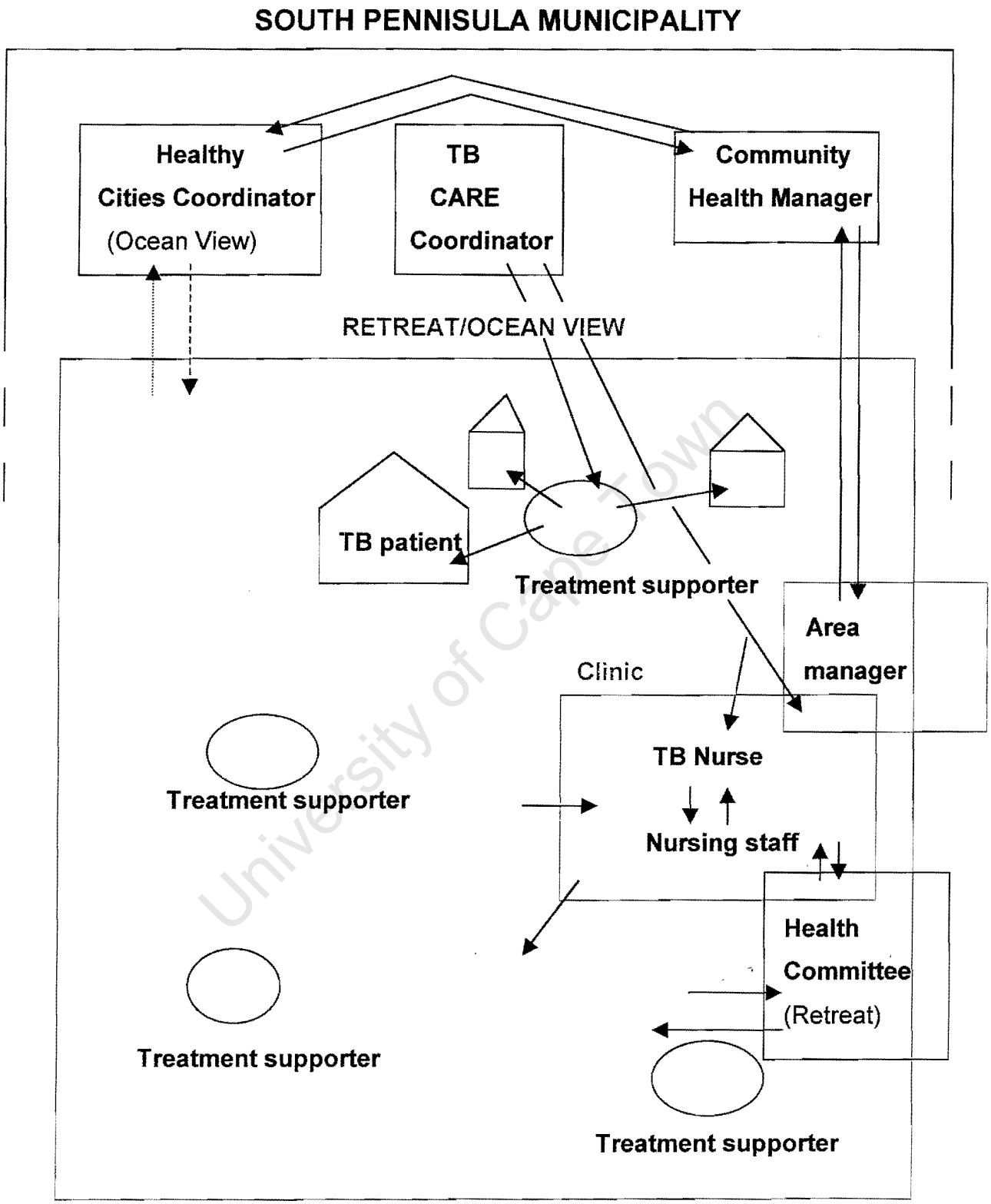

Figure 2: Stakeholders and their respective relations

4. Participants

A total number of 62 people were included in the study.

Target Group	Sample: Retreat	Sample: Ocean View	Methodology
Tuberculosis patients	❑ 10 patients: clinic-based supervision ❑ 10 patients: community-based supervision ❑ sample controlled for age, population group, and gender	❑ 10 patients: clinic-based supervision ❑ 10 patients: community-based supervision ❑ sample controlled for age, population group, and gender	❑ Structured interviews
Clinic staff ❑ **TB nurse** ❑ **Nurses** ❑ **Doctor**	❑ 1 TB nurse ❑ 4 nurses ❑ 1 doctor who works in both areas	❑ 1 TB nurse ❑ 3 nurses ❑ /	❑ Semi-structured interview ❑ Focus group ❑ Semi-structured ❑ interview
Community treatment supporters	❑ 4 treatment supporters	❑ 4 treatment supporters	❑ Structured interviews
Management ❑ **TB Care Coordinator** ❑ **Community Health Manager** ❑ **Healthy Cities Coordinator**	❑ 1 Coordinator ❑ 1 Manager ❑ 1 Coordinator		❑ Semi-structured interviews for all 3

5. Principle Themes

Three of the six main themes explored in this study are based on the principles of primary health care and on the Healthy City concept, namely equity, community participation, and comprehensive and intersectoral approach to the provision of services (Carolissen, 2000; Coulson et al., 1998; Collquohoun & Kellerhear, 1996; Beaglehole & Bonita, 1997; Matthews, 1992).

The equity theme is explored by looking at related themes of accessibility, affordability, and availability. Part of the theme of community participation is the level of community involvement in particularly health decision making, the existence and general knowledge of effective mechanisms for people to express demands and needs, the relative influence of political parties and of community-organised groups, as well as the degree of decentralised decision making.

Comprehensive and intersectoral approach to the provision of services is explored by looking at the existence of mechanisms to facilitate communication, joint policy-making, and programming. Effective communication between different levels and departments within and outside the health sector and actual intersectoral initiatives are also part of this theme.

Themes of literacy, nutrition, and living conditions, which are important in determining a person's health status, were looked at within the broader fourth category of the patient's environment/social context. The patients' perceptions of tuberculosis were also explored.

The last theme is health care management, which looks at how the two different treatment approaches are managed including issues such as communication and monitoring systems.

6. Instruments

Seven different interview schedules were developed for the various role players based on the above-mentioned themes. The questionnaires for the TB patients and the treatment supporters were translated into 'Cape Flats Afrikaans'. The patient questionnaire focused on demographics and living conditions, perceptions of their community, tuberculosis history and experience, accessibility to services, service delivery, and barriers to compliance. The questionnaire was piloted and modified where necessary.

Open-ended interviews were used with the other role players, which allowed less restricted exploration of issues. The interview questions were drawn from the literature review and are based on the above-mentioned principles. Where possible the interviews were tape recorded and transcribed. The TB nurse's

questionnaire focused on the services offered by the clinic, roles, perceptions of the community and TB patients, adherence, and general management issues. Some of these questions were included in the discussion guide for the focus groups with the other nurses, with a more general focus. Questions for the treatment supporters focused on their roles, their perception of their community, relationships with the clinic staff and with patients, and on organisational issues. The interview schedule for the coordinators/managers of TB Care, Healthy Cities and the SPM's Community Health focused on the different project aims and objectives, as well as on community participation and the management of services respectively.

7. Method

7.1 Sample criteria and sample selection

In order to explore a range of experiences of the treatment delivery system, all main role players in both areas had to be interviewed. Only the tuberculosis patients had to be sampled since all other role players – nurses, treatment supporters, area managers and others – were included in the study by virtue of their organisational position. The community and clinic-based patients were controlled for by age, gender, and population group.

As mentioned in chapter two, the selection criteria had to be widened to include as many potential participants as possible, since the population of adult smear positive pulmonary tuberculosis patients at each clinic is relatively small. The final selection criteria included diagnosed smear positive adult pulmonary tuberculosis patients, no matter how many times they have had the disease or at which stage they are in their treatment. Even though clinic-based and community-based respondents were controlled for gender, population, and age, the selection was based on the patients' availability and consent to participate.

This selection and recruitment method is limited and biased. The sample is not representative of the population. The self-selection bias was taken into consideration when analysing the data. Patients who attend the treatment at the clinic or with the treatment supervisor are more likely to comply and more likely to have a positive treatment experience. Men were generally less willing to participate, even though more men are being treated for TB. The self-selection bias also excluded those patients who are currently interrupting their treatment. This was compensated for to a certain extent, by widening the selection criteria to include patients who may have had TB before or were retreatment patients (who were either previously cured from the disease and have fallen ill again, or were non-compliant and interrupted their treatment).

In the case of community-based patients, bias could have resulted from selective referral by the treatment supporters. Unemployed patients were also more likely to be available for interviews than employed patients, further biasing the study. Other factors that biased the selection of TB patients included, poor cooperation by patients - some of whom were only comfortable answering in short sentences – and many patients who refused to participate in the study.

Since the interviews were about peoples' immediate experiences, they did not have problems with recall. Some may have, however, exaggerated or lied to please or to be overly critical. To counter these inconsistencies, the participants were made to feel as comfortable as possible, expectations discussed, and contradicting answers challenged.

The purpose of the study is not to draw generalisable conclusions, but rather to explore subjective experiences and, once the various biases have been taken into consideration, to draw on lessons learned for each area.

7.2 Interviews and Focus Groups

Interviews with the TB patients who receive clinic-based treatment were conducted in a small room next to the TB treatment room. The TB nurse would ask patients to see me once they had received or while they were still waiting for their medication. After the study objectives were explained and consent received,

the participants were asked to answer the questions in a structured interview of between 20 – 40 minutes. None of the patients agreed to having the interview tape-recorded and detailed notes had to be taken. As a thank you, patients received sandwiches.

Community-based TB patients were asked to participate in the study through their treatment supporter. Interviews were set up at a time most convenient to the patient – usually just before or after they received their medication – and took place in the lounge of the treatment supporter. The treatment supporter was asked to leave the room during the 20-40 minute structured interview.

Individual interviews were set up with the TB nurses from Retreat and Ocean View. Semi-structured interview schedules were used a guide. The interviews were an estimated 30 minutes long and tape recorded. Unfortunately due to technical problems, only the detailed notes taken during the interview could be used. The focus groups with the nursing staff at the Retreat and Ocean View clinic were less structured, encouraging uninhibited participation. In Ocean View the group consisted of 3 out of 4 and 5 out of 11 staff members in Retreat. The discussions were 30 – 40 minutes long and tape-recorded and transcribed. The doctor, who works in both Retreat and Ocean View was interviewed based on the interview schedule used for the TB nurse. The interview took place between consultations and was somewhat disjointed and short.

All community treatment supporters were interviewed in their homes at times most convenient to them – except for two, who were not available at the time. The individual semi-structured interviews of about 40 minutes were only tape recorded in a few cases, since most participants were uncomfortable with having the conversation recorded. Detailed notes were taken and transcribed.

Semi structured interviews were also used with the respective coordinators. Appointments were set up and the interview took between 30 minutes and 1 and a half hours and were all tape recorded and transcribed. The Retreat Health Committee were asked to comment on a few issues during one of their meetings.

7.3 Collection of records from authorities

Information of TB patients at both clinics for one month was collected from the clinics' TB Registers. Other relevant statistics of the clinics were received from the SPM Health Information officer. The Retreat community profile was provided by the Retreat clinic. The TB Care coordinator provided information about TB Care, past evaluation reports, and training manuals for community treatment supporters. Additional information about the Ocean View community was obtained from Statistica SA.

7.4 Site Observations

Site observations were conducted at the respective clinics, training sessions for treatment supporters, at clinic staff and community treatment supporter meetings, as well as at one Retreat Health Committee meeting. Treatment supporters' homes were visited and this treatment environment observed. Descriptions of the various contexts were made, minutes of meetings taken, and the contents of training sessions noted. Interactions between treatment providers and patients were observed and noted during the many visits to the clinics and to the treatment supporters' homes.

8. Analysis

The content analysis has been structured around the four above-mentioned themes. Within each category, the subjective experiences of the various role players are presented according to an assessment of the current situation within the two areas and to their various approaches to the three primary health care principles. The fifth theme that emerged during the analysis revolves around health care management issues. In each section, the treatment experiences in Retreat were compared to those in Ocean View. The community-based treatment experience was also compared to the clinic supervision experience. Differences and similarities are presented. The findings are further discussed in the final chapter.

Theme	Overview
Environment	Descriptions of Retreat and Ocean View: ❑ Service provider perspective ❑ Patient and treatment supporter perspective
Community participation	❑ A look at the clinics (Retreat and Ocean View) ❑ A look at the treatment supporter groups (Retreat and Ocean View) ❑ A look at TB Care ❑ A look at Healthy Cities Project
Equity	❑ A look at the clinics (Retreat and Ocean View) ❑ A look at the treatment supporter groups (Retreat and Ocean View) ❑ A look at TB Care ❑ A look at Healthy Cities Project
Comprehensive Approach to the provision of health care services	❑ A look at the clinics (Retreat and Ocean View) ❑ A look at the treatment supporter groups (Retreat and Ocean View) ❑ A look at TB Care ❑ A look at Healthy Cities Project
Health Service Management Issues	❑ Community Health management approach ❑ Treatment supporter management approach ❑ Incentives ❑ Communication ❑ Monitoring and Record keeping

CHAPTER FOUR
FINDINGS AND ANALYSIS

1. ENVIRONMENT: Descriptions of Retreat and Ocean View communities

The social environment is considered to include living conditions, levels of nutrition and education, economic conditions, as well as belief systems and the nature of community health services. This context has been recognised as very important in determining the health status of communities. (Mechanic, 1992; Mydral, 1986; Fullimore et al., 1993; Ellis, 1997; Edington, 1997).

The perceptions of the patients, nurses, TB Care Coordinator (who also acts as the social worker), Healthy Cities Coordinator and the treatment supporters were collected to gain some understanding of the environments TB patients live and health care workers work in. Even though the descriptions are from different viewpoints and from different areas, they all describe similar hardships and challenges.

Main Findings: Environment

1. *Living Conditions*

- ❑ Income:
  - Retreat and Ocean View have a similar overall income distribution – with 43% unemployed in Retreat, compared to 49% in Ocean View (Census 1996)
- ❑ Employment:
  - Participants in Ocean View had fewer job opportunities and alternative sources of income than Retreat
  - In both areas TB patients rely on the support from the clinics (45%), the NGO TB Care (20%), welfare (10%), and/or families (70%) for their survival
  - More participants in Retreat were employed than in Ocean View
- ❑ Nutrition:
  - Levels of nutrition were generally very poor in both areas
  - 50% of the participants did not have regular meals
- ❑ Housing:
  - Lack of housing was a major concern in both areas
  - 65% of participants interviewed in Retreat lived in a house, compared to 25% in Ocean View, where 45% TB patients lived in flats
  - 25% of participants in Retreat and 30% in Ocean View lived in shacks
- ❑ Overcrowding:
  - Overcrowding is a problem in both areas: there are many shacks and additions to houses
  - 80% of participants in Ocean View had to share their one- bedroom accommodation with between 4 and 8 other people

Main Findings: Environment - continued

2. *Social and Developmental Concerns*

- ❑ Similar concerns expressed by service providers and patients:
  - alcohol and drug abuse
  - crime
  - safety
  - abuse
- ❑ Development:
  - Ocean View seemed less resourced than Retreat
- ❑ Education:
  - Overall: 7% of Retreat residents and 12% of Ocean View residents did not have an education
  - 30% of TB patients interviewed in Retreat and 40% in Ocean View did not have any educational background

3. *Clinics*

- ❑ General Health Concerns of both clinics:
  - TB
  - Teenage pregnancies
  - Malnutrition in children
  - HIV (higher in Retreat)
- ❑ Tuberculosis:
  - Retreat had a larger case load than Ocean View
  - Ocean View clinic used less treatment supporters than Retreat clinic
  - TB incidence rate for men and women were very similar
  - There was a high infection rate between family members and friends
  - There was a high number of infections among children in Ocean View

1.1 Living Conditions

Retreat is an urban area located on the Cape Flats, 23 kilometers by train away from Cape Town's CBD covering about 30 square kilometers. According to the 1996 Census an estimated 33 371 people lived in Retreat.

An estimated 14 009[2] people live in Ocean View - almost double the population of Retreat. It lies approximately 80 kilometers outside of Cape Town and the only mode of transport is taxis, unlike residents in Retreat who can also commute by train and by bus. According to the TB Care Coordinator, residents perceive themselves as *"castaways"* partly because there are very few job opportunities in the area and because of the relatively isolated location of Ocean View.

Ocean View is divided into smaller "suburbs" such as Atlantic Heights and Mountain View[3]. These areas are known by the locals as "Beverly Hills", "Ghost Town", "Hungry Hills", and "Lapland". These suburbs reflect the divisions of the community along class and status lines. "Beverly Hills" is the more affluent area, where as "Lapland" consists mostly of shacks. The

[2] The Census 1996 figures are questionable because until only recently has one area of Ocean View – Mountain View- even been recorded on the municipal maps. It seems therefore unlikely that these residents were included in the census.

[3] Mountain View lies on the outskirts of Ocean View and consists of 11 hostel like buildings. In 1986 104 families were removed from squatter camps in Fish Hoek and Noordhoek to Mountain View as a temporary solution. After 15 years they are still there – with more people having been moved there from Kalk Bay in 1999. It has only until a few months ago been recognised as a formal residential area. The hostels were electrified last year.

Healthy Cities Coordinator added that Ocean View is also polarised between ANC and NNP supporters.

1.1.1 Income

Of the 33 371 Retreat residents counted in the 1996 Census, 43% did not have a monthly income, 10% earned R1- R500, 14% earned R 501- R1500, and 11% earned R1501 – R3500. 4% earned more than R 3500 per month.

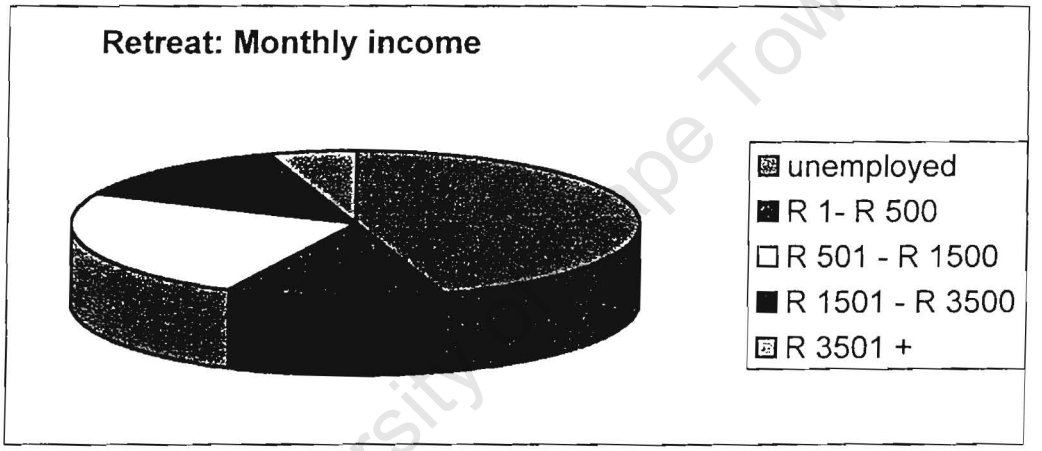

Figure 3: Income distribution within Retreat (Census 1996)

Compared to the monthly income of Retreat residents, the Ocean View community appears to be slightly poorer than residents in Retreat – with a marginally higher unemployment rate (49% versus 43%) and less people earning in the highest income group (2% instead of 4%).

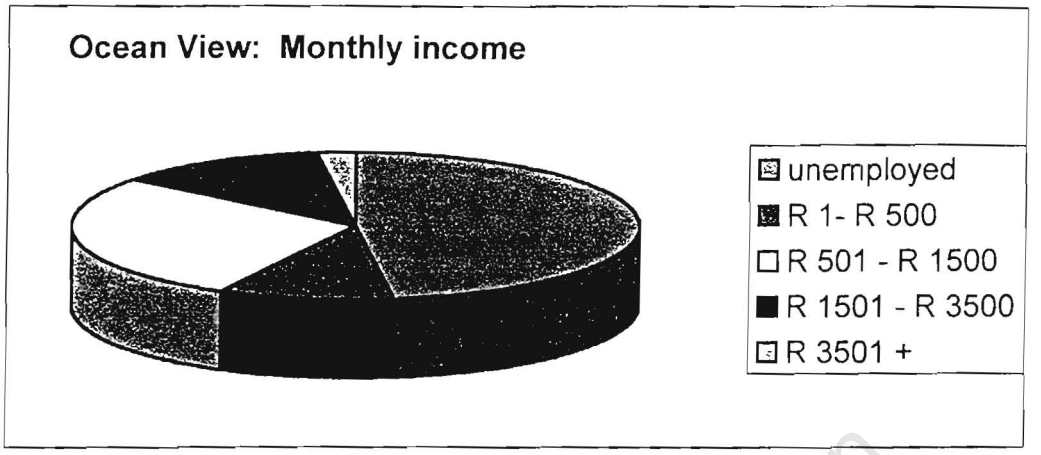

Figure 4: Income distribution in Ocean View (Census 1996)

1.1.2 Employment status

All clinic-based patients interviewed were unemployed at the time of the interview. The working TB patients generally receive their DOTS supervision at their workplace or with community treatment supporters. Overall unemployment was high amongst TB patients – especially in Ocean View. More community-based patients interviewed in Retreat (30%) were employed than those in Ocean View (0%).

Job opportunities were perceived as non-existent by half of the Ocean View respondents. Some people were working in the building and fishing/crayfish industry, which is seasonal. In Retreat some people thought that there were a few jobs in the area, for example as shop assistants, but these opportunities were very limited.

1.1.3 Sources of Income

The majority of patients in Retreat and Ocean View were dependent on the financial support of their families (siblings, partners, parents, pensioners). Only 30% of patients interviewed received such support, highlighting the importance of assistance from the TB nurse, the treatment supporter and social worker, as well as the need for donations.

Other respondents tried to earn some money by doing odd jobs, such as washing cars or helping with shopping bags. 10% of the patients interviewed were receiving welfare or children grants and 20% were relying completely on donations from TB Care (R45 voucher for three months). None of the patients spoken to received a TB grant, even though some were planning to apply.

Not having a source of income was very stressful for patients, who felt helpless and hopeless. They perceived their future as uncertain since they could not afford rent or food and are dependent on others' goodwill. Their disease was but one of many concerns of the patient.

1.1.4 Nutrition

According to the Retreat Community Profile (Gossman & Langeveldt, 1999), white bread - and junk food among youth - made up a large portion of residents' diet. In 1998 the clinic saw 8 children with severe malnutrition.

Half of the patients interviewed did not have regular meals because they have no income. In Ocean View two patients were arrested for taking out seafood in a restricted area. 45% participants relied on the clinic for powdered milk and porridge, breakfast club meals on a Thursday, and donations of vegetables and fruit. Their average daily meals consisted mainly of tea or coffee and cereal or bread. Many of them usually did not have enough food for dinner.

TB patients who had three meals a day, including fresh vegetables and fruit, were generally young men and women who had at least a standard 3 school education, were employed or who were receiving a pension. Those who were unemployed lived in a house with supportive families/mothers who earned a regular income.

1.1.5 Housing

Within Retreat there was no available land for new housing developments, despite a growing community. The Princess Vlei Primary School has become an informal settlement, home to 220 families – with 100 of its residents under the age of 18 years.

In Retreat 65% of the patients interviewed lived in a house, 25% lived in a shack on someone else's property and 10% of persons interviewed lived in a flat. Life in a shack was difficult – *"[I]t is either very hot or very cold and the*

wind gets in when it's stormy." – Patient, Retreat. Everyone had access to clean water, even though sanitation is a problem for those living in shacks.

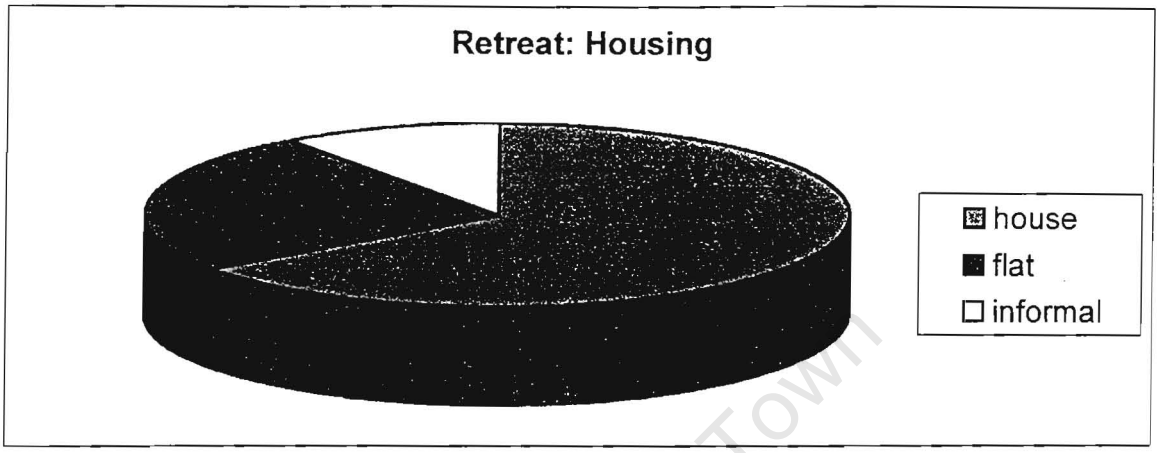

Figure 5: Participants' living arrangements in Retreat

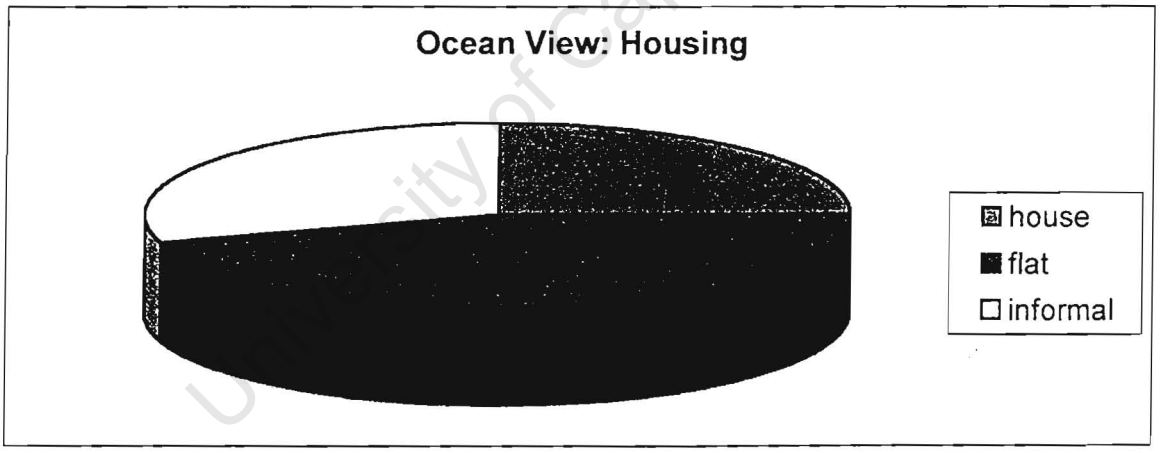

Figure 6: Participants' living arrangements in Ocean View

The majority of patients (45%) interviewed in Ocean View live in flats in the vicinity of the clinic, while the others live in shacks (30%) or in houses (25%).

Even though houses were being built in Ocean View, the treatment supporter thought that they were not of very good quality.

1.1.6 Overcrowding

Overcrowding is a major concern in both areas. According to the Retreat Community Profile (Gossman & Langeveldt, 1999), in some cases up to 35 people live in a 2-bedroomed home, sleeping in shifts. There are many shacks, wendy houses and caravans in the yards of homes. Some council housing applicants have been on the waiting list for about 10 years. A very similar situation existed in Ocean View. According to the information provided by the "Open Door" (NGO working in the area) director, an average of 10 people share a dwelling in Ocean View.

Even though the size of participants' homes in Retreat ranged equally from a one-bedroom home up to three bedrooms, the majority of participants had to share with between 4-8 other adults. One patient had to share a small house with 11 others. *"I have to share my bed with four children" – Patient, Retreat.*

As in Retreat, most participants in Ocean View have to share their home with between 4 to 8 other people – even though 80% live in a one-bedroom space.

1.2 Social and developmental concerns

1.2.1 Social concerns

The TB Coordinator and the clinic staff shared similar perceptions of the social problems the two communities were facing. In Retreat only specific areas seemed troubled with shabeens, substance abuse and gangsterism, whereas it appeared to be a more widespread problem in Ocean View. Both areas, however, have high rates of poverty, unemployment, housing shortages and overcrowding.

Participants of both areas were alarmed about the same social problems in their neighbourhoods. The greatest concern to patients was the widespread alcohol and drug abuse, followed by crime and theft, as well as unemployment, violence, abuse and rape. Most of the treatment supporters complained about the corrupt police.

The majority of male participants in Ocean View and Retreat had tattoos indicating current or previous gang membership. 65% of the men spoken to have served time in prison. 15% of the women interviewed admitted to currently or having previously been in an abusive relationship.

Participants' sense of safety in Retreat was stronger than in Ocean View. Half of the Retreat respondents had a sense of safety where they live, whereas most people in Ocean View only felt safe when they stayed at home in the evening, or did not feel safe at all. According to police officers in Retreat and Ocean View, factors which generally contribute to the high incidence of crime are alcoholism and drug abuse, unemployment, overcrowding, and gangsterism (Gossman & Langeveldt, 1999).

Most people had difficulty speaking about community issues because they felt that it was none of their business what is happening in their neighbourhood – it is considered to be nosey.

The challenges facing the Ocean View community seemed more concentrated. *"There is widespread elderly and other physical abuse, gangsterism and drug dealing, incest, and corruption in Ocean View." – TB Coordinator.*

At the time of the study, one crèche teacher was being investigated for mismanagement of funds. Poverty was of particular concern in Mountain View, where there was also a high concentration of social problems, such as sexual abuse. According to the TB Care Coordinator, young girls are prostituting themselves at early ages to earn an income.

1.2.2 Development

The only visible developmental organisation working in Ocean View is "The Open Door" – which is part of the Valley Development Project – and deals primarily with abused women and children. Compared to Ocean View, Retreat has several job creation projects. CAFDA, an NGO actively involved in developmental work and with 15 full time social workers in its employ, is one of several visible resources available to the Retreat community in Retreat. The only skills development activities available in Ocean View are for the physically disabled. For other kinds of skills development training residents have to travel 3 kilometers outside of Ocean View.

1.2.3 Education

The majority of TB patients interviewed did not have any educational background. Most participants had completed their standard 3 – 6. Only a few had finished their standard 8 (23%) or matric (15%). In Retreat more female respondents than males had not attended school, while in Ocean View more men had no educational background.

According to the 1996 census, 7% of the people counted in Retreat did not have any schooling, compared to 12% in Ocean View. A large proportion of people in Retreat (44%) and in Ocean View (47%) finished their schooling up to and including Grade 11. One should also take into account participant's

reluctance to be truthful about their actual educational level. Some claimed to have attended Std. 6 but were unable to read their name. According to a treatment supporter, most people living in Ocean View are illiterate, which he believes is linked to the high incidence of teenage pregnancies.

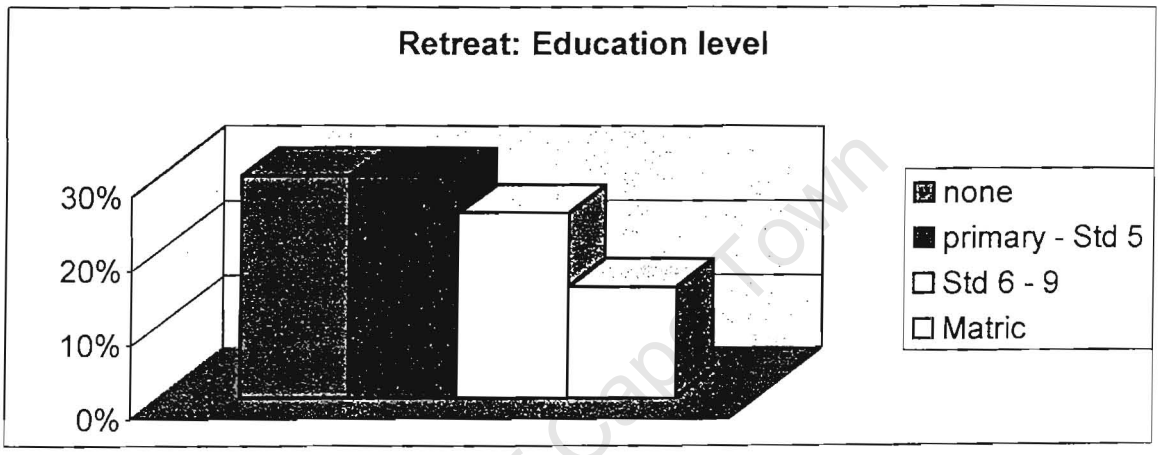

Figure 7: Participants' education level - Retreat

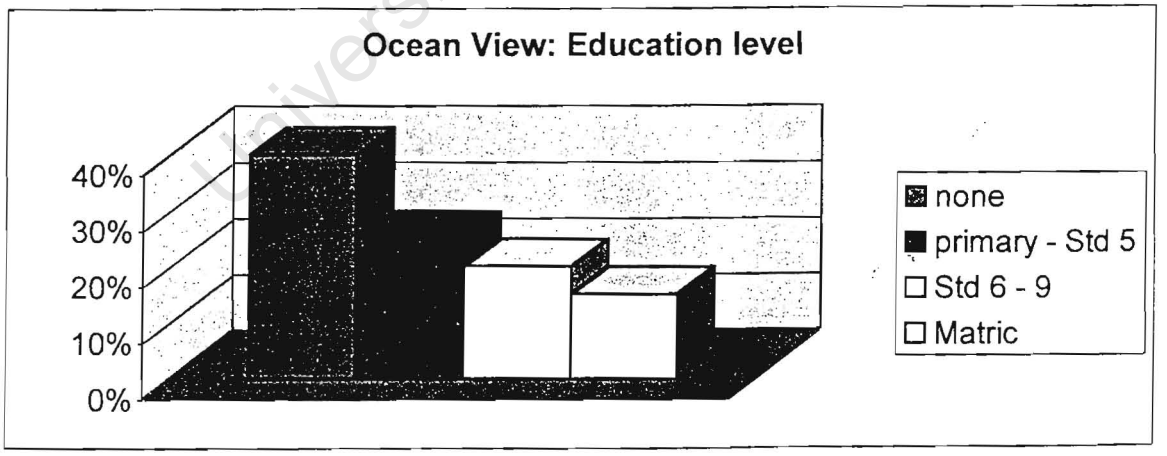

Figure 8: Participants' education level – Ocean View

1.3 Retreat and Ocean View clinics

1.3.1 Health concerns

According to the nurses, a close correlation existed between such concerns and the health problems they dealt with at the clinic – such as malnutrition in children and TB. Besides TB, the nurses considered teenage pregnancies as another health concern, which was increasing at an alarming rate. A nurse recalls seeing a pregnant girl of 15 years – *"...but so were 10 other girls in her class."* – *Nurse, Retreat.* The high rate of psychiatric cases in Ocean View was attributed to prolonged substance and other abuse or to the numerous intermarriages.

1.3.2 Tuberculosis

Even though Retreat had the third highest TB incidence rate in the South Peninsula district, the smaller Ocean View, followed closely with the fifth highest incidence rate.

The high TB rates, the once low compliance rates (in 1997/8), and the sanitation problems, as well as Ocean View's relatively isolated location, were the reasons why the area was selected as pilot Healthy Cities project.

Retreat clinic nurses attended to between 50-60 TB patients per month. The Ocean View clinic had a somewhat smaller monthly caseload of between 30 -

40 TB patients. For the second quarter of 2001 the majority of TB patients at both clinics were supervised at the clinic – 38% in Retreat and a high 75% in Ocean View (see Figures 9 and 10). Ocean View patients were only recently given the option of receiving supervision in the community, which explains the high number of clinic-based patients. The Retreat TB nurse seemed to have greater support than the Ocean View TB nurse – in terms of a lightened workload – from the treatment supporter group.

Compared to Ocean View, the doctor (who worked in both areas) believed that patients in Retreat seemed more compliant. She attributed this to the slightly better economic conditions in Retreat.

Five Retreat TB patients were infected with HIV, compared to two Ocean View TB patients who were HIV positive. The HIV incidence rate in Ocean View is lower than in Retreat.

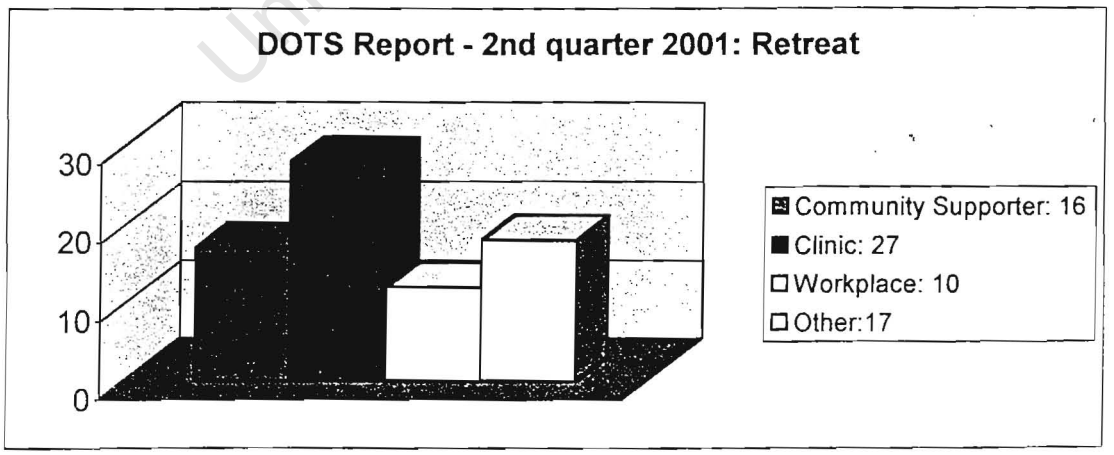

Figure 9: Retreat clinic DOTS report for the second quarter 2001

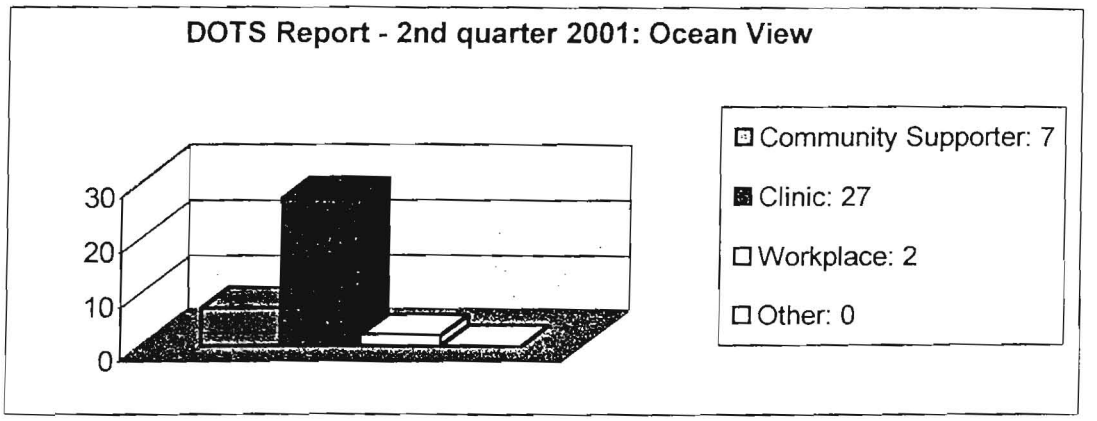

Figure 10: Ocean View DOTS report for the second quarter of 2001

According to the DOTS clinic records for Retreat and Ocean View (Figure 11 and 12), the majority of TB patients between October 2000 to March 2001 were between 20 and 39 years old (affecting their economic activity). These SPM community health statistics[4] do not, however, reflect the very high incidence of primary TB among children between 0 and 14 years of age in Ocean View. At the time of the study, the TB nurse recorded 42 adults and an alarming 42 children with the disease.

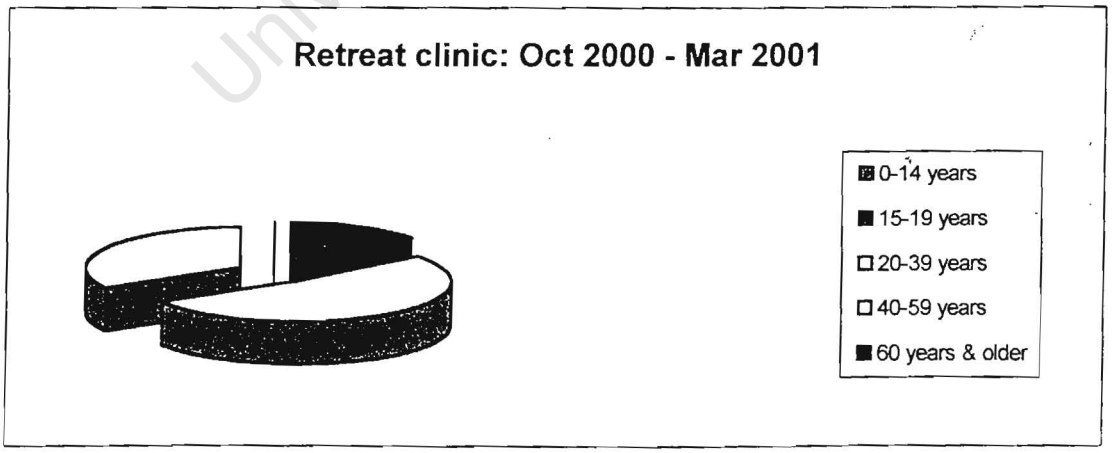

Figure 11: Retreat clinic TB records: age

[4] The statistics can only be compiled for the previous quarter and therefore did not reflect the situation at the time of the study.

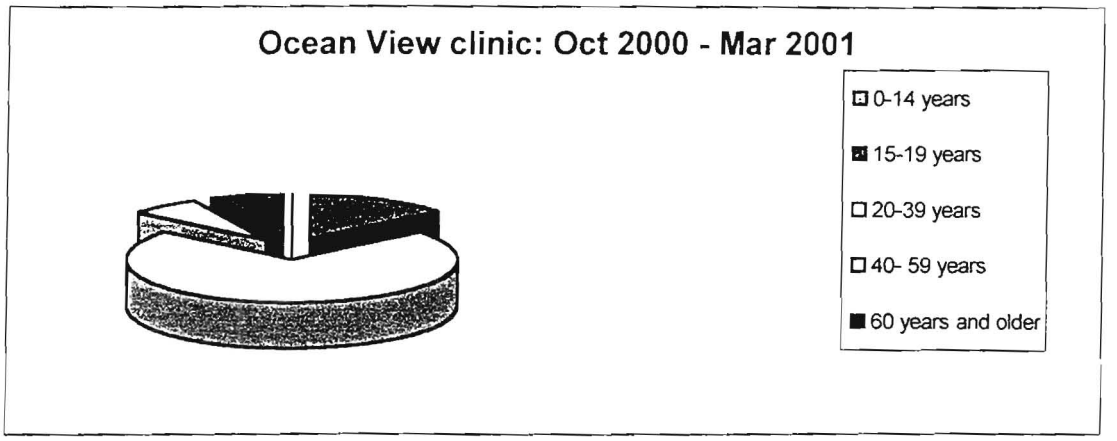

Figure 12: Ocean View clinic TB records: age

70% of participants' family members have had or were currently infected with TB. Many patients had infected their children before being diagnosed and taking any medication. This is a great concern especially in Ocean View, where overcrowding is prevalent.

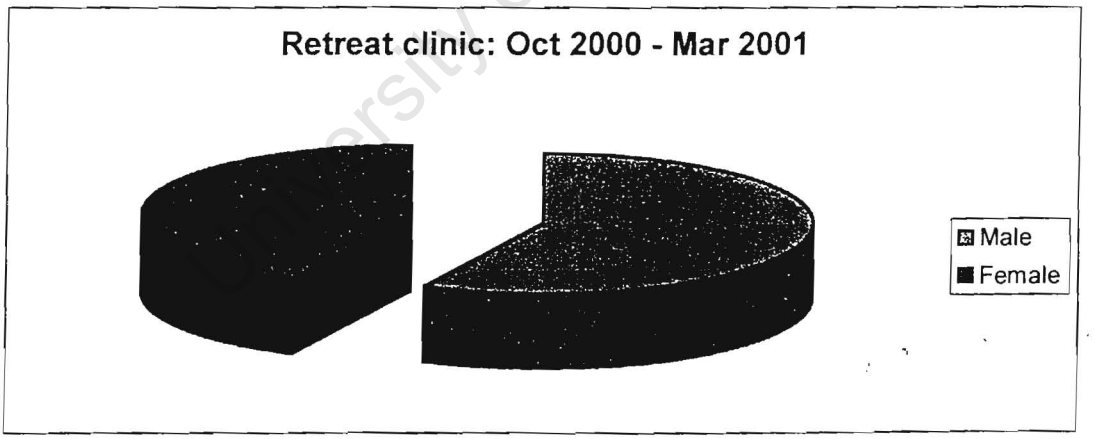

Figure 13: Retreat clinic TB records: gender

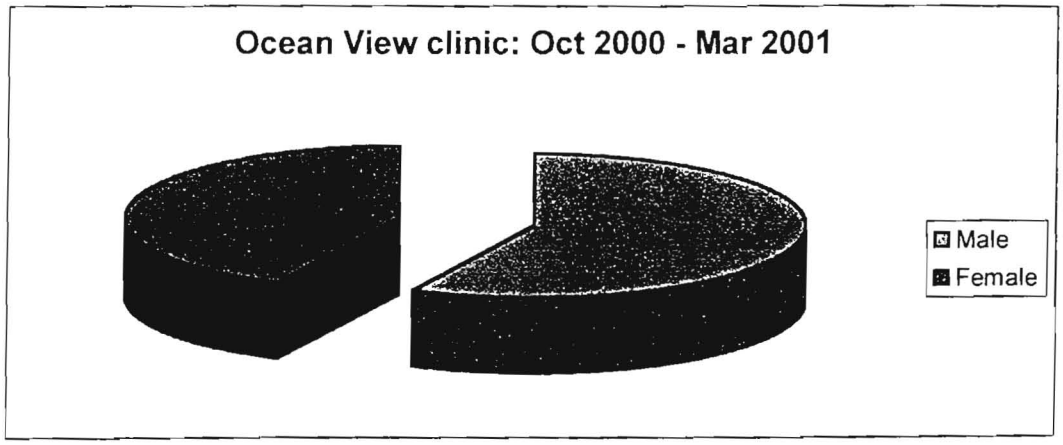

Figure 14: Ocean View clinic TB records: gender

The records (Figures 13 and 14) also reflect that the disease is slightly more predominant in men than in women. In both Ocean View and in Retreat men make up 57% of the total TB cases.

2. PERCEPTIONS OF TUBERCULOSIS

Patients – both community and clinic-based patients and service providers in Ocean View and Retreat shared similar understandings of the disease and of compliance.

MAIN FINDINGS: PERCEPTIONS OF TB

1. Cause of infections
   - Participants had a relatively good understanding of the disease and its possible causes, as well as their need to comply with the treatment regime.
   - Patients attributed the cause of their illness to their environmental living conditions, unhealthy lifestyles, and from infections from family members, friends, or prison cellmates.
   - In Retreat 81% of the TB case load are first time patients, whereas in Ocean View the number of new TB cases (48%) and re-treatment cases are almost the same (52%).

2. Compliance
   - Most participants believed that the necessity of supervised treatments was for their own good.
   - Enhancers of compliance included fear of infecting others, accepting responsibility for own health, as well as a good relationship with the nurse or treatment supporter.
   - Barriers to compliance include work, homelessness, substance abuse, side effects and taste of the medication, and accessibility (weather, distance to clinic).

2.1 Cause of infection

The patients' views on the cause of TB seemed to be very similar to those of the medical model. The disease was understood as a germ that has infected a person, whose environment or whose lifestyle is currently not healthy.

Most of the TB patients interviewed attributed their illness to their environmental and living conditions – as well as the conditions in prison (damp, cold, drug abuse). Other reasons mentioned include infection from family members, substance and physical abuse, and stress.

Compared to Ocean View, more first time TB patients (75%) than re-treatment patients were interviewed in Retreat. This reflects the overall TB population in both areas. Of the TB cases at the Retreat clinic between October 2000 and March 2001, 81% were new cases and only 19% were re-treatment cases.

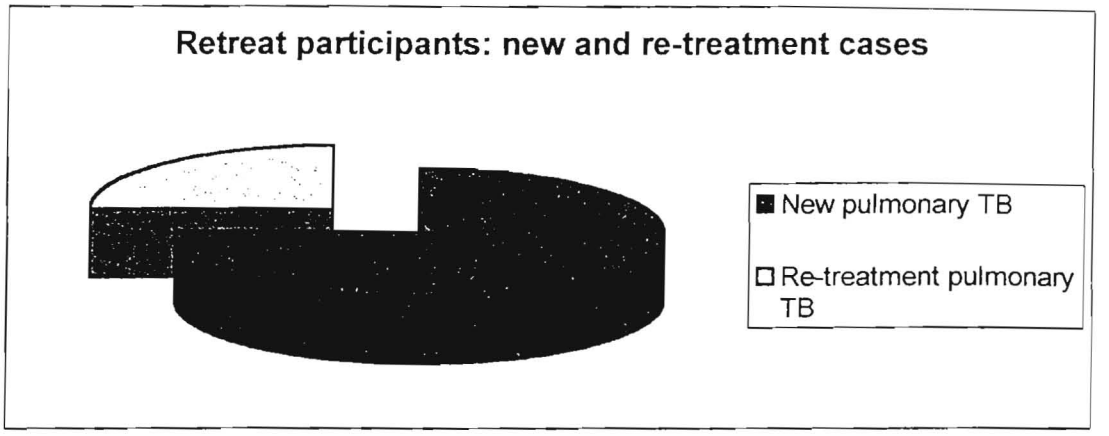

Figure 15: Retreat participants: new and re-treatment cases

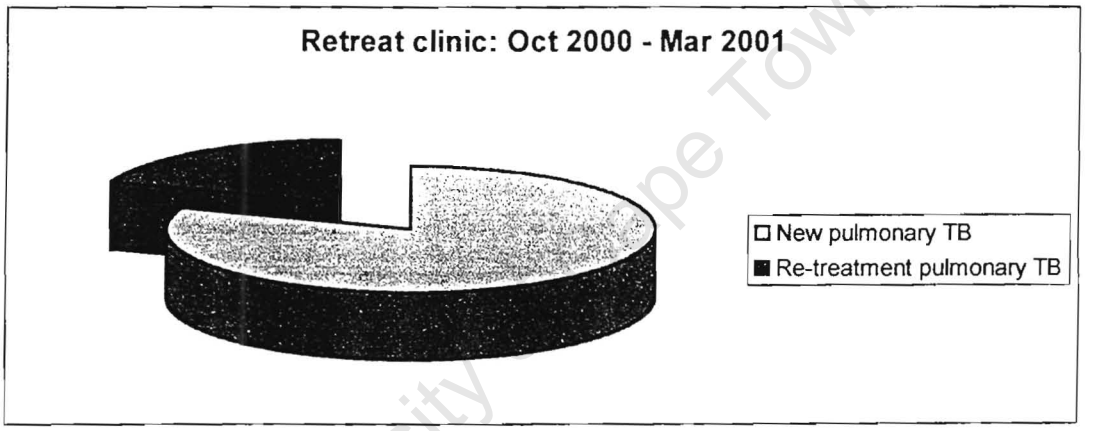

Figure 16: Retreat clinic TB records: new and re-treatment cases

In Ocean View almost an equal amount of patients interviewed had TB for the first (40%) and for the second time (35%), while four patients (20%) have had TB for the third and even fifth time. This too reflects the situation in Ocean View. Between October 2000 and March 2001 there were 48% new cases and 52% re-treatment TB cases in Ocean View. Unfortunately the clinic records did not reflect how many of the re-treatment cases were non-compliance/treatment interrupters and how many had previously been cured.

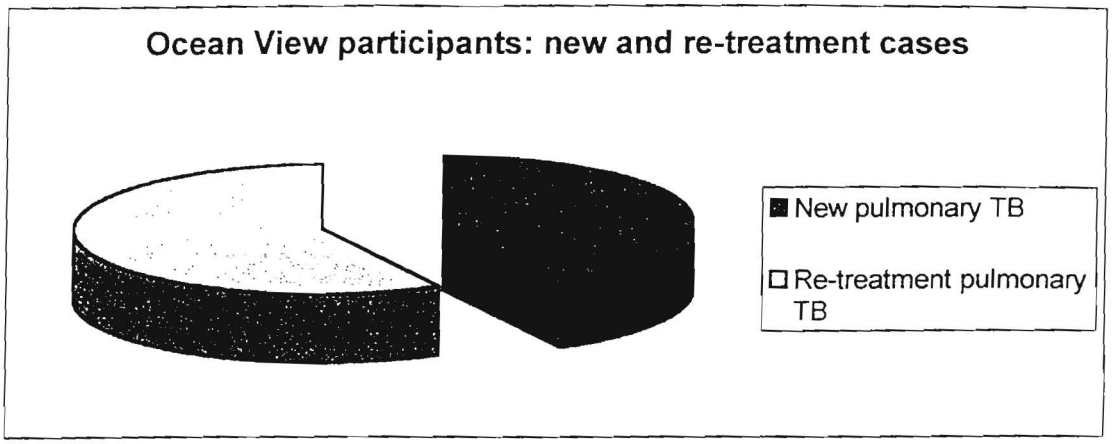

Figure 17: Ocean View participants: new and re-treatment cases

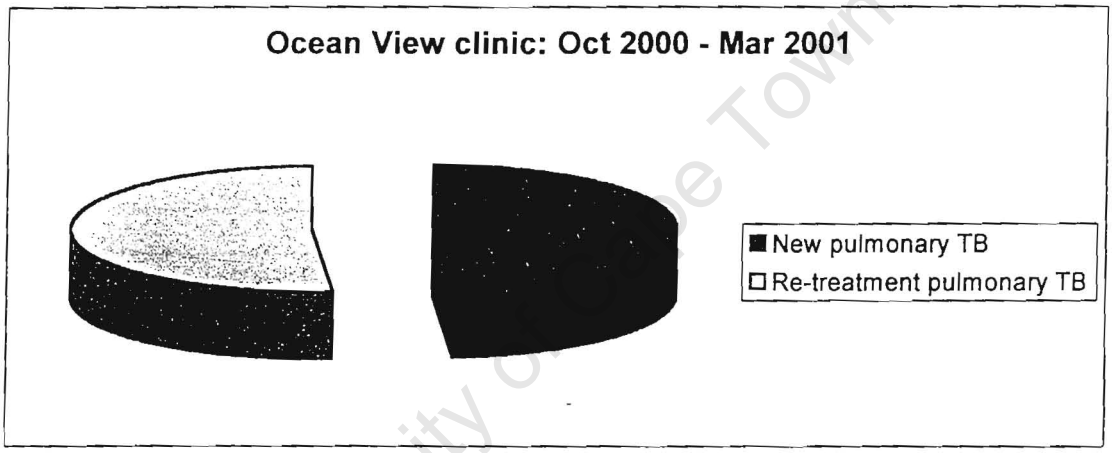

Figure 18: Ocean View TB clinic records: new and re-treatment cases

The majority of the participants had been cured from tuberculosis before falling ill again. Even though compliance is a problem in some cases, it is not an issue for those patients who have completed their treatment and were cured. Many patients were returning with second or third TB infections (particularly in Ocean View), which could be attributed to their unhealthy living conditions.

2.2 Compliance

2.2.1 Perceptions on supervised treatment

The study explored the meaning of the anti-tuberculosis treatment in the everyday lives of both the patient and the service provider, supporting the notion that compliance is value-laden.

The majority of participants were compliant at the time of the study. This did not necessarily reflect the overall situation at the clinics, since patients who attended the clinic or visited the treatment supporter were included in the study (biased selection) and therefore were more likely to be compliant with their treatment.

Their views on the necessity to be supervised by another person – nurse or treatment supporter – varied. Several patients felt that they were responsible enough to take their pills on their own. Others would prefer to take the tablets closer to their home. Some respondents, however, believed that it was a necessary evil because some people do not take their medication. Others just accepted this strategy unquestioningly. The majority of patients – those that were compliant and reliable – believed that DOTS was for their own good and that their health was very important to them. This is a strong theme throughout the interviews – with both community-based and clinic-based patients.

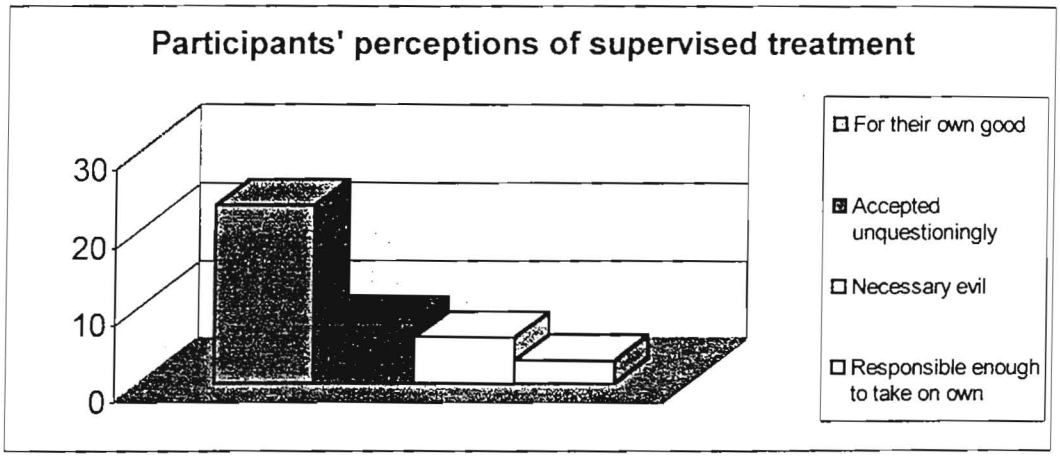

Figure 19: Participant's perceptions of supervised treatment

2.2.2 Enhancers of compliance

What motivated respondents to come to the clinic for DOTS - despite the many barriers - was mainly that they could see that the treatment was working and that they wanted to get well. TB prevented them from leading normal lives and from working and earning a living. Some patients also stated that they were concerned about infecting others if they did not take their medication on a regular basis.

Both TB nurses and treatment supporters agreed that their relationship with the TB patients was very important in motivating people to come for their medication. Treatment supporters gave their clients day-to-day encouragement and advice – such as on nutrition - to help them complete

their treatment. It was, however, up to the patients themselves to adhere to the treatment.

2.2.3 Barriers to compliance

According to the TB nurses and doctor, some reasons why patients generally were not compliant included work, being out at sea for long periods of time (fishermen), homelessness, and substance abuse.

The treatment itself was perceived as very long and expectations of patients to seek supervision every day were considered to be very high. From the treatment supporters' experience, people who neglect themselves and have problems (such as unemployment) were more prone to alcohol and drug abuse, which they saw as a major contributor to defaulting. A treatment supporter's client was drinking, had defaulted and subsequently infected all four children in the house.

What made the treatment difficult for patients included the side effects – such as nausea – as well as the weather, distance to the clinic, and that one has to have something to eat before taking the medication. Some patients complained about the bitter taste and size of the pills. One respondent suggested that they should have more privacy.

None of the patients interviewed could think of a strong enough barrier that would prevent them from regularly attending the clinic for their TB treatment.

3. COMMUNITY PARTICIPATION

MAIN FINDINGS: Community Participation

1. Perceived overall levels of community participation:
   - Community participation was not important to the respondents.
   - Service providers perceived both communities as disempowered and unwilling to take the initiative.
   - Low levels of community participation in both areas - particularly in Ocean View – due to poor sense of safety. Participants also did not feel empowered enough to influence their community.

2. Community participation within the clinics
   - Retreat had a functioning Health Committee, whereas there was no Health Committee in Ocean View.
   - The main objective of the Health Committee was to ensure smooth service delivery.
   - The representation of service providers outweighs that of community members by far.
   - Using volunteers (treatment supporters) was defined as community participation.
   - The establishment of food gardens was relatively successful in Retreat. The vegetables harvested were sold to pay for more seedlings. Only one TB patient was involved.
   - The food garden in Ocean View was temporarily put on hold due to lack of resources (financial and staff shortages).
   - There was little awareness of the food garden project amongst TB patient participants.

MAIN FINDINGS: Community participation continued

3. Community participation and treatment supporters

- The treatment supporters' overall purpose is to lighten the workload of clinic staff, provide a more accessible and personal service, and a way of raising the awareness of the community.
- Treatment supporters are very active in their communities. In Ocean View the supporters were also active in other projects as a group.

4. Community participation and TB Care

- The NGO focused on recruiting literate women, who are willing to work as volunteers and have the health and welfare of the community at heart.
- Selection criteria did not seem sufficient because a large number of trained supporters were not active in the Western Cape – limiting community participation. In Retreat only 5 out of 15 and in Ocean View 5 out of 7 trained supporters were still active.
- Each treatment supporter group was represented at the TB Care management body, which is the NGO's decision-making body.
- Groups were still relying on the TB Care Coordinator to drive initiatives (in Retreat) or to liaise between clients and clinic staff (in Ocean View).

5. Community participation and the Healthy Cities Project in Ocean View

- Community participation in the Healthy Cities project was not very high.

MAIN FINDINGS: Community participation continued

- Some of the reasons include the planning of and method of communicating the meetings to the community, the historically poor relationship between municipality and the community, the political divisions within Ocean View, as well as the impression that there is no progress or action.
- The treatment supporters were actively involved in the Healthy Cities' cleaning campaign.

3.1 Perceptions of community participation

Community participation was not considered to be very important by the majority of participants. Only 10% of participants were part of a committee – church committees in Retreat. No one attended forum meetings or received any feedback about such meetings, even though a handful of respondents in both areas were aware of them. Reasons for not attending meetings were generally related to their concern for safety. No one had knowledge of Health Committee meetings. Only one person in Retreat knew of a leader within their community (church).

Even though the level of participation seems higher in Retreat – with a functioning Health Committee – the general interest of interviewed patients in community participation, seemed to be limited.

The nurses in Ocean View believed that the community members were unwilling to participate in community activities because "*they have been spoon fed for all of these past years. They have never been encouraged to do things for themselves.*"- *Nurse, Ocean View.* They perceived the respective community as dependent on them (and other service providers) and as unable to take the initiative. Even the TB Care Coordinator perceived the communities – especially Ocean View – as disempowered.

Community participation in Retreat and Ocean View seemed low as a result of the high rates of crime and gangsterism in the areas. Participants, particularly in Ocean View, felt that it was not safe to walk to evening meetings. Community members in both areas believed that they had no influence over their neighbours - drug dealers and shabeen owners – whom they feared. In Ocean View parents had little control over their own children, who were committing crimes and abusing substances.

3.2 Community participation within the clinics

The two clinics had different levels of community participation. In Retreat, a Health Committee met very regularly. Its members consisted of representatives of the day hospital staff and clinic staff (nurses, doctor, social workers), as well as a few community members. The committee's main focus was on the logistics and service delivery of both the day hospital

and the clinic. Its objective was to bring the different service providers and the community together to resolve issues around service delivery. An example of the agenda items included the discussion around the unfriendly and messy day hospital, the unsafe path between the clinic and day hospital, and about whether or not street vendors should be allowed to use the health department's property.

Even though a Health Committee was established in Ocean View, it no longer existed.

Both clinics made use of volunteers – treatment supporters – to assist the nurses with their duties, such as with the weighing of babies or immunisations. This was also considered to be community participation.

The establishment of a food garden for and by the TB patients was initiated about a year ago by both clinics with varied success. Treatment supporters were trained in Retreat to assist with the preparation of the garden. A small patch of clinic land was set aside for the garden. In the Retreat garden a variety of vegetables were planted, of which most of the harvest was sold to raise money to purchase more seedlings. Only one TB patient and his girlfriend were involved in the Retreat garden.

The Ocean View garden was less successful and was temporarily put on hold. Two TB patients helped the TB nurse to prepare the bed with compost which she paid for out of her own pocket. The patients, however, lost interest after having to wait to get involved in the garden because of bad weather and other complications. The clinic had not yet asked for donations for the garden. They plan to start it again in the following year.

Most patients – in Retreat and in Ocean View – did not know about the project, which was meant to include them. Only one patient in Retreat and two in Ocean View were aware of the food garden or were involved in it.

3.3 Community participation and treatment supporters

The overall aim – from the clinic's perspective - of having treatment supporters was to lighten the workload of the nurses with respect to TB treatment, by offering community supervision. They are also considered to be more able to provide the patients with a more personal and accessible care. The clinics also perceived the training and use of community members as another way to increase the community's awareness of the disease.

The treatment supporters in both areas were in one way or another, actively involved in their community. In Retreat the supporters acted individually, assisting their church groups and other organisations as volunteers. In Ocean View the treatment supporter group had worked together with the Healthy Cities project on cleaning campaigns. Individual members were also actively involved in their churches or in Forums (such as the Action Committee for housing in Ocean View, Valley Child Protection Committee, Church committee and the Sports Board). Generally, the treatment supporters were more informed about meetings and other community activities even though their knowledge was vague.

3.4 TB Care's role in community participation

3.4.1 Recruitment of treatment supporters

TB Care perceived the mobilisation of the community as very important for TB Care's aim of empowering them. They hoped to achieve this approach to community participation by training women within the various communities.

By focusing on training women, TB Care hoped to change their status within their households and their communities. Their capacity was built, not only in community DOTS, but also in skills such as meeting

procedures and minute taking. TB Care also believed that the incentive – even though only R 30 per client per month – was financially empowering for most of the trained women, who were able to contribute to the household income and thereby increase her power and status.

The treatment supporters were recruited from advertisements placed in the local newspaper and through announcements at churches and mosques calling for *volunteers*. The incentive was not advertised because TB Care prefers supporters to see it as a thank you instead of an income. The selection criteria for treatment supporters included that the person is willing to work as a volunteer, is literate, and has the health and welfare of the community at heart. The treatment supporters are then finally chosen together with the clinic staff.

According to the SPM community health manager, NGOs need to develop better and uniform selection criteria. The number of non-active treatment supporters was increasing in the Western Cape. In total, 700 community members have been trained to supervise TB patients. It was unclear how many of these people were still active and how many were temporarily or permanently inactive. As mentioned earlier, in Retreat five out of fifteen supporters and in Ocean View five out of seven, were active. There is a need for a monitoring system that can record the status of the treatment supporters, as well as the reasons for their inactivity. Training is time

consuming and even though it may create greater awareness within the community, the SPM community health manager did not think it should be a completely random exercise.

3.4.2 TB CARE Management representation

TB Care recognised the importance of taking community participation beyond mobilising people, to providing them with a forum for decision-making. Every treatment supporter group elects one representative who takes part in the TB Care management meetings.

According to the TB Care Coordinator, treatment supporter groups should ideally become more independent from the TB Care Coordinator – in terms of running meetings, fundraising and organising events related to awareness raising and relationship building with the TB patients.

Its treatment supporter groups were, however, not yet self-sufficient and independent from the TB Care Coordinator. Even though the Ocean View group had taken the initiative for organising many of its own events and becoming involved in the Healthy Cities cleaning campaign, they did rely on the TB Care Coordinator for guidance and to liaise between members and the clinic. The Retreat group relied on the TB Care Coordinator to drive

initiatives. They were not used to working together as a group and had their own activities, which were keeping them busy.

3.5 Community participation and the Healthy Cities project

Since its launch, two community workshops had taken place. According to the Healthy Cities Coordinator, even though they planned the workshop according to the ward councilor's advice, there was a disappointing turnout by the community. The assumption was that the response was poor because they had planned the workshop on the last Saturday of the month when residents shop. The Coordinator admitted that they also made the mistake of coming to the meeting with preconceived ideas about the major issues within Ocean View. They assumed that the community would agree that TB and waste management were the main challenges in Ocean View. A planning committee was established consisting of 18 representatives of sport and religious organisations, schools and crèches, the RDP Forum and Valley Development Trust. It was decided to hold a second workshop in order to get more representative feedback from community members about their needs and concerns.

Before the workshop, the Valley Development Trust withdrew from the process, citing insufficient community involvement and that the process was

"a NNP hidden agenda". The turnout of the second community workshop was also disappointing. Only two people from the planning committee were present. People were asked to raise their issues and concerns. Out of this workshop, a new working group was formed. After requesting a presentation by the Valley Development Trust and acknowledging its important role, the Valley Development Trust agreed to take part in the Healthy Cities working group. Other members included the Ocean View Enrichment centre, crèches and schools, as well as the RDP Forum – who are linked to many other NGOs and community representatives working in the area.

The community is not only economically, but also politically divided, which has made community participation driven by the local government especially difficult. This highlights the need of Healthy Cities to continue to be politically neutral.

Another challenge facing the Healthy Cities project, was the poor relationship between the Valley Development Trust and the SPM Housing department. This impacted on the Healthy Cities project, because even though they may have had a problem with a particular department, the project is seen as part of the SPM municipality. They were all perceived in the same negative light.

The TB Care treatment supporters in Ocean View – together with the health inspector and the South Peninsula (who donated black bags) - were actively involved in the Healthy Cities cleaning up campaigns. They helped organise the crèches and schools to clean their area. These campaigns have been very successful.

The treatment supporters' involvement in the cleaning campaigns was considered by TB Care as voluntary and not discouraged. *"The group is concerned about the health of the community and their commitment is also valuable to other projects." - TB Care Coordinator.* The TB nurse, however, felt that the supporters should not be distracted from their community DOTS duties. One treatment supporter no longer attended the Healthy Cities working group meetings because there seemed to be no progress.

4. EQUITY

MAIN FINDINGS: Equity

1. Equity and clinic-based treatment:
   - TB treatment was easily accessible for clinic-based patients.
   - The distance to the clinic was acceptable for most patients. For those who had to walk far, the nurse gave more than the daily dose of medication at a time until they were transferred to the community treatment supporters.
   - Equity was enhanced by the very good participant relationship with the clinic staff, particularly the TB nurse. The relationship between the patients and the Ocean View nurse seemed even more personal.
   - The majority of participants did not complain about the social worker or the doctor, who worked at both clinics.
   - There was a problem with drug availability towards the end of the study at the Retreat clinic.

2. Equity and community-based treatment:
   - Relationships between TB patients interviewed and treatment supporters was perceived to be just as good as with the TB nurse, particularly in Ocean View.
   - The reason why participants preferred community-based treatment to clinic-based, was only that it was more convenient (distance) for the patients.
   - Treatment supporters had good relations with their patients, getting to know them and their families.
   - The TB treatment with most treatment supporters was more like a social visit: patients were often offered something to drink and eat.
   - Equity had only recently been improved in Ocean View, with the gradual introduction of treatment supporters.

4.1 Equity and clinic-based supervision

For the majority of clinic-based patients living in Retreat and in Ocean View, the clinic - and their treatment - was accessible. Most patients spoken to live about 5 - 10 minutes walk away from the clinic. 20% of participants had to walk 30 minutes or more everyday to receive their treatment at the clinic. To assist them, the TB sisters in Retreat and in Ocean View occasionally gave them extra tablets to take so that they did not have to come everyday. They would later be placed with a community supporter. None of the patients had to wait for their treatment. As in Retreat, the TB nurse in Ocean View always prepared the patients' containers the previous day.

Even though the service seemed to run without difficulties, the availability of drugs to treatment supporters affected equity at the Retreat clinic. When asked whether there have ever been shortages of drugs, two treatment supporters in Retreat claimed that they had to mix and share the tablets of patients.

The clinics were, nevertheless, perceived as accessible. People's associations of both clinics were generally positive. *"I like coming to the clinic – it's the first thing I do when I get up – I go to the clinic."* – *Patient, Ocean View.* Only a few patients associated long queues and waiting with the clinic.

The main reason why community - and clinic-based patients felt positive about their clinic was due to the very good relationship between participants and the clinic staff - especially with the TB nurse.

The TB nurse in Ocean View was described by community and clinic-based patients as approachable and friendly. Even though they saw her rushing up and down the corridors and realised that she was busy, they knew that she would always make time for them if they needed to chat about personal problems and to answer questions related to TB.

All participants – clinic-based and community-based - described the Retreat TB nurse as very friendly, even though they only spent a few minutes per day with her. She always asked about their well being and was talkative. Small gestures, such as wishing a patient well, remembering their name, and enquiring about problems gave patients the impression that the TB nurse cared about participants. All interviewed patients felt supported by the TB nurse because she encouraged them and gave some of them food donations. The relationship with this TB nurse seemed slightly less personal and affectionate than the one between the patients in Ocean View and their TB nurse. For illiterate patients, the TB nurses in both clinics marked the containers in some special way.

The Ocean View nursing staff in general seemed more personal and approachable than the Retreat staff. Even though both TB nurses were very committed to their responsibilities, the Ocean View nurse appeared to be more involved in her patients' lives.

The other nurses at the Retreat clinic were perceived as friendly, even though the patients do not really know them well. *"If they had been rude I would not have come."- Patient, Retreat.* Some did, however, complain about a few of the Retreat nurses because they were shouted at. According to one Retreat treatment supporter, the clinic was overburdened with too many clients and understaffed.

In Ocean View, the other three nurses are perceived as approachable and friendly. The only complaint was directed at the receptionist of the day hospital, who was rude to patients and was accused of favouritism.

The average waiting time for patients to see the doctor was about 30 minutes. None of the clinic-based respondents had grievances about the doctor. Two community DOTS patients from Retreat complained that the doctor did not examine them during the consultation, which was a concern for them.

Those patients who have met the social worker gave positive feedback about her as well, with the exception of the long waiting time to see her. Only 5% of participants complained because she did not give them money or the kind of help they wanted. Others were assisted with children grants, TB Care vouchers and other problems.

4.2 Equity and community-based supervision

Access and equity were further improved by the introduction and use of community DOTS supporters in both areas.

Most participants relied heavily on the emotional support from their treatment supporter. Since the treatment supporters usually have fewer patients than the TB nurse, they should be more able to spend quality time with them. Nevertheless, all community-based patients described their relationship with their treatment supporter *and* their TB nurse as very good. One Retreat patient, however, preferred being treated at the clinic because he did not think that the treatment supporters would be as well trained as the nurse. Most respondents believed that they received just as much support from the treatment supporter as from the TB nurse.

The clinic was too far away from where the majority of community DOTS patients lived, which made their treatment adherence inconvenient and difficult. Most of the community DOTS respondents lived between 20 and 30 minutes away from the clinic. Being supervised by someone in the community made their treatment more accessible.

Generally treatment supporters in Retreat and Ocean View described their relationship with the patients as friendly and good. Treatment supporters said that they get to know the patients and their families – and the patients in turn get to know them. Regularly treatment supporters offered their patients tea and sandwiches or fruit, which makes their visit more like popping in to a friend or neighbour than a treatment.

In Ocean View, however, the majority of trained treatment supporters lived in an area with a low TB incidence rate. TB cases had not been mapped before the identification and training of treatment supporters to establish where there was a need for treatment supporters. The "black spot" of TB incidence at the time of the study was in "Lapland" (Atlantic Heights), however, there were no community supporters in the area. This resulted in underutilisation of treatment supporters, since most supporters were not receiving patients. It also limited access and equity for many patients, who had to continue to receive their treatment at the clinic. The problem was to administer DOTS in "Lapland" at the non-governmental organisation, *Open Door.*

5. COMPREHENSIVE APPROACH

MAIN FINDINGS: Comprehensive Approach

1. Comprehensive approach: TB Treatment Services
   - Primary health care at the Retreat and Ocean View clinics was more focused on disease specific and curative treatments than on preventative measures.
   - TB Care recognised the need to move away from the disease specific focus. They were training its members in nutrition and HIV/AIDS issues and encouraging supporters involvement in other health related projects.

2. Comprehensive approach: Nutrition
   - The promotion of food supply and basic nutrition of clinics and treatment supporters was understood only within the welfare framework. Many patients relied on this support offered by clinics and treatment supporters.
   - The food garden initiative was a step towards approaching this component of primary health care (PHC) more developmentally.
   - The treatment supporters' and the nurses' support was not very sustainable or regular.

3. Comprehensive approach: Health Education
   - Health education and awareness was generally disease specific, with only the minority of patients interviewed been addressed by the nurses about other health issues, such as HIV/AIDS, STDs, family planning, and nutrition.
   - Treatment supporters educated their patients more on a one-to-one basis. Only a few yearly awareness raising events were organised by the supporters or clinic in their community.

MAIN FINDINGS: Comprehensive approach cont.

- The additional training of treatment supporters allowed them to offer a more comprehensive treatment. The Ocean View group was still waiting to be trained in HIV/AIDS and nutrition.

4. Comprehensive approach: Partnerships
   - Nurses did not pass on information to patients about organisations that could assist them with food, clothing, shelter or substance abuse problems. They relied on the social worker for such referrals.
   - Only the Ocean View nurses met with other organisations (Open Door and Healthy Cities).
   - TB Care did not have any strong partnerships with government departments, the Healthy Cities project or other organisations – including other TB NGOs.

5. Comprehensive approach: Healthy Cities project
   - Its focus is on creating enabling environments through a comprehensive approach.
   - It had only initiated a few diverse projects at the time of the study, which addressed some of the environmental health, local economic development and nutrition issues.

5.1 Comprehensive approach: TB Treatment Services

Clinics offered some preventative but mostly curative services - including family planning, TB, STD, HIV counselling – focusing on teenagers, mothers, and babies. According to the nurses at both clinics, the focus remained on treating diseases and not their causes.

There did, however, seem to be a very limited attempt at offering more than disease-specific treatment. Even though they did not offer any advice or treatments outside of the tuberculosis framework. In Retreat the TB nurse spoke to 10% of participants (who had served time in prison) about HIV infection and asked them to be tested. No other issues were discussed with the rest of the participants. In Ocean View the TB nurse discussed family planning and vaccination with 30% *of* the patients interviewed. She also asked one patient to encourage her family members to come to the clinic for sputum testing.

Generally the TB nurse was aware of the living conditions of her patients. She could have used this knowledge to help a person living in a shack by suggesting a worm treatment. Conversations could also have included methods of preventing the spread of HIV. It seemed as though such contacts with patients were not utilised to their fullest potential.

Even though the SPM community health management's focus was on DOTS and curative services, they expected that treatment supporters should be trained in other health issues besides TB.

TB Care was aware of the need to move away from its exclusive focus on TB and started training its treatment supporters in nutrition and HIV/AIDS. New treatment supporters were trained by TB Care staff over several days. Participants were given a manual *"Tackling TB Together – Training Manual*

for TB Treatment Supporters". The training was interactive and included the following themes: understanding TB, preventing TB, identifying adults and children with TB, receiving TB clients, treating TB clients, looking after clients, and educating the community about TB.

The aims of the training included preparing supporters to, for example, encourage clients to choose healthy lifestyles, collect sputum, counsel, keep records, deal with the challenges of clients who do not take their medication, abuse substances, and clients with multi-drug resistant TB and HIV.

The Retreat treatment supporters had been trained in a separate HIV/AIDS and nutrition course, while the Ocean View group was still waiting to attend those courses at the time of the study. Most of the treatment supporters had attended other training – unrelated to TB Care. Such training - included counselling, home care, substance abuse and First Aid - had given them additional skills they could draw on when necessary. Since the treatment supporters had more time than the TB nurses for each patient, they were also more able to provide more comprehensive care based on their additional training.

5.2 Comprehensive approach: Nutrition

The promotion of food supply and basic nutrition is one of the 8 components of primary health care. Both clinics interpreted this objective within the welfare framework, rather than according to the developmental approach (such as local economic development or health education). This was also the case for the treatment supporters, who donated food and shared it with their patients.

The food garden initiative was successful in terms of moving the clinics towards a more comprehensive approach to health care. It was an example of the Health department reaching out beyond its directorate and networking and learning from other organisations in the community to address health issues - including TB - in a more creative way. Unfortunately only a few community members were involved in the food garden, resulting in limited knowledge transfer and capacity building.

The breakfast clubs aimed to provide one meal a week to TB patients. The clinics relied on the donations from the local community, which were not always regular, for the meals. All together 35% of clinic-based patients interviewed had regular meals at the breakfast club. Others received donations of fruit and vegetables (Retreat).

The breakfast club in Retreat and in Ocean View was at times supplemented by contributions made by the nurses. The TB nurse was also responsible for fundraising for the club. Even though the breakfast club and other donations for patients were considered to be important for compliance, these incentives seemed difficult to sustain on a regular basis.

All of the treatment supporters in both areas had the health and welfare of their community at heart. They were all generous, offering their patients food and a cup of tea when they came for their treatment. Others also cooked food for the destitute and for TB patients out of their own accord.

5.3 Comprehensive approach: Health education

Despite the many other duties, the clinics were attempting to balance the curative focus with little health education. The TB nurse plays an important role in educating the TB patient about TB and other health issues. The information patients remembered from the TB nurse – in Ocean View and in Retreat - included the importance of finishing the treatment, nutritional food, and of taking the medication regularly or else running the risk of becoming infectious. The nurse encouraged one patient to stop smoking mandrax. Three literate patients were given information booklets[5] about TB, infection,

[5] "Kos & Gesondheid – Tuberkulose" sponsored by Shoprite Checkers and SANTA and " How you can beat TB" sponsored by Medical Association and SANTA

and nutrition, which they, their families and friends thought was very useful (Retreat).

In Ocean View the clinic manager attended a meeting organised by the schools, which targeted the youth and involved fighting crime. At this meeting the students needs were identified. The clinic manager gave them talks on HIV, TB and other health issues. The clinic also organised a puppet show in Mountain View, with the objective of teaching residents about TB.

Treatment supporters had previously only been expected to administer the DOTS and support and educate the patient. TB Care was starting to encourage the treatment supporter groups to take a more proactive role in raising the community's awareness around TB. Again, TB Care acknowledged the need of treatment supporters to move away from strictly only giving tablets to patients, to reaching out to the rest of the community about general health issues. The new Ocean View group has been more involved in these activities than the more established Retreat group.

The Ocean View treatment supporter group made the community aware of TB through their launch. They organised a march through the community and invited TB patients and other guests to celebrate the start of community DOTS in the area. Even though there are occasions when treatment supporters organise such events, these are seldom and raising levels of

awareness occurs more as a result of a one to one basis with patients, their families and occasionally with neighbours.

Other prevention work TB Care was involved in was workplace training and awareness raising. Employers and employees were given crash courses on DOTS and guidelines of how to identify and support the patient. According to the doctor, TB Care organised a 'blitz' –and went from door-to-door in Ocean View informing people about TB and collecting sputum. They managed to identify some people infected with TB this way. TB Care's main focus, however, was DOTS, which is curative.

5.4 Comprehensive approach: Partnerships

As in Retreat, the Ocean View clinic staff were aware of other organisations but had limited contact with them. Organisations the nurses were aware of and with whom they worked in Retreat included CAFDA, TB Care, and the Health Committee. In Ocean View, the nurses knew of the Open Door and Valley Development Trust, as well as the Healthy Cities project. The clinic manager in Ocean View attended the monthly Healthy Cities meetings, along with representatives from Waste Management and Environmental Health.

The group work offered by TB Care focused on first building the patients' self-esteem and then offering skills training. The group work identified alcohol and drug abuse as a major problem affecting compliance. The TB Care Coordinator invited a person from Alcoholics Anonymous (AA) to speak to the TB patients, but it was not successful because this person did not speak their language and was not approachable. Even though it is the AA's policy that people attend their meetings out of free will, the social worker had tried to refer them and in some cases "blackmailed" them to go to AA by threatening to no longer give them food vouchers.

According to the SPM community health manager, social work plays a very important role in encouraging patients to complete their treatment.

It seemed that the clinic staff relied heavily on the TB Care Coordinator (who works as social worker as well) for referrals. The TB Care Coordinator, however, only worked as social worker at each clinic once a month. The Retreat community had access to the many CAFDA social workers, whereas the Ocean View residents were less fortunate. People could make use of the *Open Door* social workers for issues only related to abuse. There was a need for more social workers in Ocean View.

TB Care refers clients to SAPS, Alcoholics Anonymous, SANCA, district surgeons, clinic staff and doctors, Child Welfare, women abuse groups, maintenance courts, and other social organisations.

Partnerships between TB Care and government departments and other organisations were limited to asking for assistance and to referrals. It seemed as though no integrated work was done. This was especially true for the many different TB NGOs who are in some cases duplicating a lot of work.

According to the TB Care Coordinator no real relationship existed between TB Care and the Healthy Cities project in Ocean View at the time of the study. She believed that other NGOs took part in the meetings but that TB Care had not been invited. She was, however planning to invite the health inspector to the treatment supporter meetings. Considering that the Healthy Cities project originally identified TB as a major concern, it seemed strange that TB Care was not invited to join the working group. This possibly reflected the Healthy Cities coordinators lack of knowledge about all of the developmental organisations active in Ocean View.

5.5 Comprehensive approach: Healthy Cities project

The Healthy Cities project is an example of a strategy that attempts to approach health in a truly comprehensive and multi-sectoral way, recognising the social rather than medical definition of health.

The Ocean View Healthy Cities project attempted to start creating an enabling environment through various projects by looking at environmental health, local economic and nutrition issues. Addressing some of the concerns raised at the second community workshop, the project managed to build two taxi ranks with public ablution blocks and run several successful cleanup campaigns. They have also started addressing the poor trading facilities. The food garden was also set up with their support. At the time of this study, the project had just completed a Health Assessment Survey of 350 community members and they were waiting for the analysis results on which they were planning to base future objectives. The project had also established communication links to other projects in the area – for example with the food garden in Retreat.

6. HEALTH CARE MANAGEMENT

MAIN FINDINGS: Health Care management

1. Clinic management:
   - The SPM simplified the clinic's foci to 2 main areas: 1. new smear positive cases and 2. to completed patients.
   - This seemed to have a positive impact on the other areas, including decreased treatment interruption.
   - The SPM also ascribed its higher cure rates to increased management involvement and support, as well as to the hard work of dedicated nurses, especially the TB nurse.
   - Staff morale was a problem in Retreat, where the TB nurse felt more supported by the community treatment supporters.
   - The lack of financial resources and space was a problem in Ocean View.

2. Treatment supporters management:
   - The TB Care Coordinator was responsible for 9 community-based projects in the SPM as well as for the respective social work. This left her with very little time to manage and monitor the groups.
   - Set guidelines and a more standardised service for TB NGOs will be needed in the near future – including guidelines of the treatment supporters' roles.
   - A concern raised by the TB nurse about the Retreat group was that the members did not attend their monthly meetings regularly and did not work well as a group.
   - The Ocean View TB nurse did not believe that the treatment supporters were doing their job.
   - Poor management may have jeopardised the success of the community-based treatment.

MAIN FINDINGS: Health Care management cont.

3. Incentives

3.1 Incentives for TB patients:

- The TB Care food vouchers were assumed to encourage compliance.
- Only a very small amount of patients received these vouchers due to the strict selection criteria, even though many patients relied on these food vouchers for survival.
- The voucher system was difficult for the NGO to sustain.

3.2 Incentives for Treatment Supporters:

- These incentives were considered as tokens of appreciation.
- Some supporters depended on these payments for survival. The system was open to being misused due to the poor monitoring system of the NGO and clinic.
- The incentive system was also difficult for the NGO to sustain.

3.3 Incentives for clinic staff:

- The incentive systems had recently been introduced and welcomed by SPM clinics.
- The SPM utilised the limited political support to motivate and encourage staff.
- The recognition of the nurses' hard work – instead of taking credit for it - was very important.

4. Communication:

4.1 Retreat:

- The relationship between the TB nurse, treatment supporters, and TB Care Coordinator was relatively good, based on the many years they have all worked together. This freed up the TB nurse and allowed for successful clinic-based treatment despite poor support from other nurses.
- The treatment supporters did not work well together as a team and had limited communication amongst each other.
- The group also had limited contact with the TB Care Coordinator.

MAIN FINDINGS: Health Care management cont.

- Overall there was poor communication and support amongst the clinic staff.

4.2 Ocean View:

- There was poor communication between TB nurse, treatment supporters and TB Care Coordinator largely due to poor communication, the TB nurse's lack of trust and understanding of the roles and skills of the treatment supporters.
- The TB nurse did not feel supported by the community-based treatment supporters.
- The treatment supporters in turn did not feel utilised to their full potential. The treatment support group worked relatively well together and engaged – as a group - in other health projects in their area.
- As with the Retreat treatment supporter group, there was limited communication with the TB Care Coordinator and the group.
- The clinic staff supported each other, which allowed for successful clinic-based treatment despite the lack of support from the treatment supporters.
- Poor communication threatened the success of the community-based treatment.

5. Monitoring Systems:
   - TB nurses were overburdened with administrative work.
   - The existing monitoring systems was meaningless to clinic staff. Feedback was only received very late – making it useless as a management tool.
   - SPM staff were trained on monitoring and evaluation systems and statistics. For the Ocean View nurses this resulted in increased insight, whereas the Retreat nurses perceived it as duplication.
   - Treatment supporters in both areas were monitored infrequently and inconsistently by the TB Care Coordinator.
   - Poor clinic and NGO records prevented verification and measuring of indicators related to community-based treatment.

MAIN FINDINGS: Health Care management cont.

- The DOTS strategy was not strictly adhered to by nurses and some treatment supporters. There were also no clear guidelines for service providers about the extent to which they should directly observe the patients' treatment. This flexibility was considered, on the one hand, to be a way to build trust between the service provider and the patient, and on the other to be compromising the DOTS treatment strategy.

6.1 Clinic management

6.1.1 SPM management perspective

The South Peninsula municipality took a slightly different approach to fighting TB than other districts. It was the most successful region in the Western Cape in terms of high cure and compliance rates.

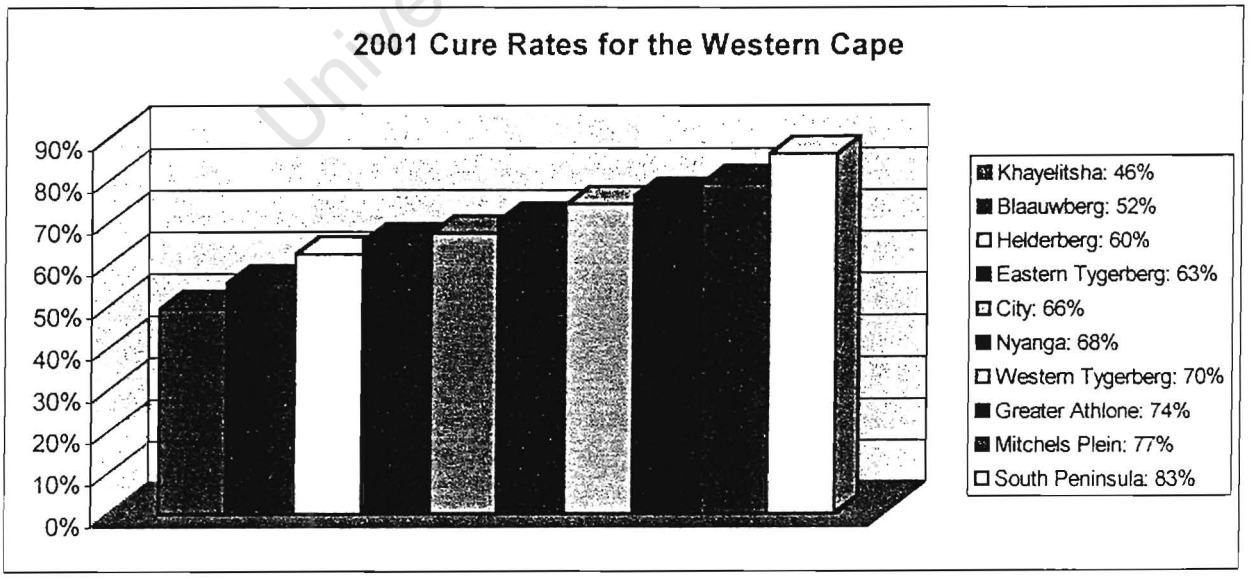

Figure 20: Cure rates of Western Cape clinics in 2001

MAIN FINDINGS: Health Care management cont.

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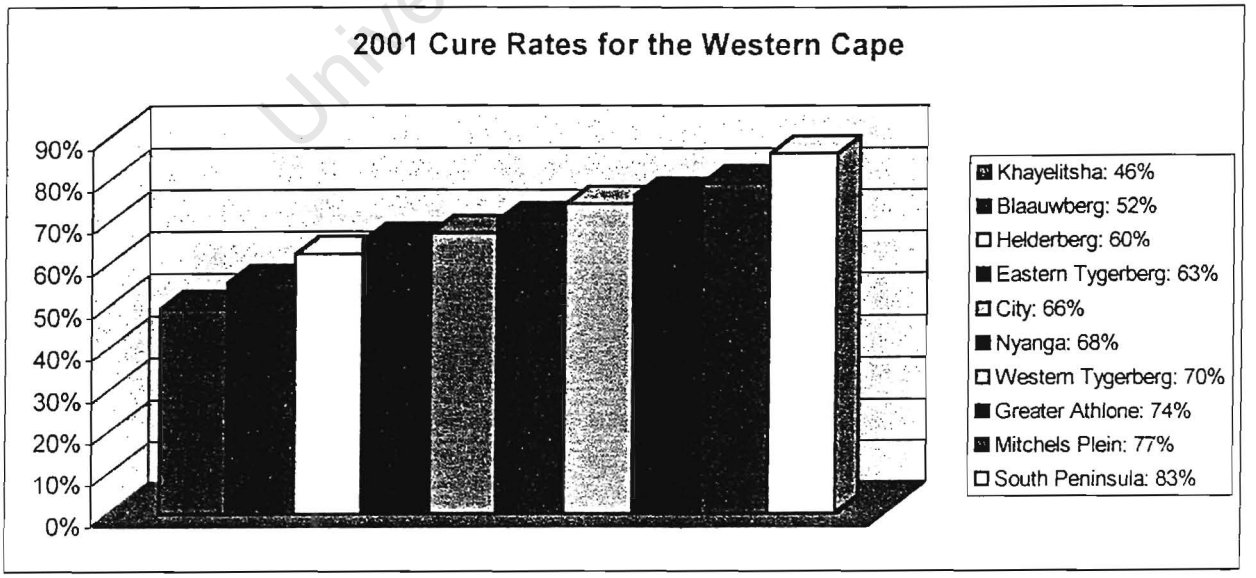

Figure 20: Cure rates of Western Cape clinics in 2001

The main concept behind this success was the clinics' focus on curing the patient as quickly as possible instead of concentrating on the wider prevention and multi-sectoral approach to fighting TB. The SPM Community Health manager focused on simplifying the activities of the TB nurse, encouraging communication and sharing of experiences between clinics, and on acknowledging the hard work of the clinic staff. This process introduced in the SPM clinics had been successful in terms of high cure rates and, according to the manager, was an important lesson for them in learning how to simplify.

Activities were simplified by first only focusing on *new smear positive* cases. The treatment interrupters were considered as too difficult to influence and gave nurses a sense of failure.

According to the manager, many patients complete their treatment but have not been tested again to prove that they have been cured. The second focus of the SPM management strategy was on patients who had completed their treatment but had not been tested to see if they are cured. Following up and obtaining a sputum sample from those patients seemed achievable and had a direct impact on the overall cure rates (closing the gap between completions and cures).

One problem highlighted by the SPM Community Health manager herself was that in the other districts the community health managers did not get involved

enough at clinic level, handing over responsibility for TB control to the clinic managers, who needed support.

TB Coordinators had been appointed and were not managing the clinic staff sufficiently. The coordinators ended up doing the tasks that the clinic staff had no time for, instead of empowering and supporting the staff in their duties.

6.1.2 Clinic perspective

The nurses in Retreat and Ocean View ascribe their successful cure rates to hard work. A TB nurse has many responsibilities – ranging from clinic supervision of patients, relationship building, record keeping, meetings, treatment supporter support, and fundraising activities. From their experience, both TB nurses agreed that there should only be one person responsible for TB, instead of rotating the responsibility as was still the practice in some clinics.

Some nurses did not respond positively to the SPM management's new approach of focusing only on the new smear positive cases, claiming that it may have simplified the records in some way, but it did not accurately reflect the work they still had to do.

Both TB nurses agree that management is quick to criticise them when the compliance rates drop. *"Management picks on me for little things – which makes me angry. They are out of touch with what we are doing." – TB nurse, Retreat.*

There was a lot of pressure on the clinic staff in both areas because of staff shortages. The result if this was that the TB nurse was not always able to do home visits or follow up with patients who missed their treatment. This did – in part – affected the morale of staff in Retreat.

In Ocean View staff morale was not a problem. The four nurses worked closely together and had good team spirit with the administrative staff and general workers. *"Empathy and support is very important to me." - Clinic manager, Ocean View.* Nevertheless, the staff shortage and lack of money *"to jack up facilities"* was perceived as a problem and affected their job satisfaction. Their clinic has only four consultation rooms – far too little considering the number of patients they see on a daily basis.

The TB nurses and the TB Care social worker complained that the lack of space was a problem in terms of privacy. In Retreat nurses and patients walked in and out of the treatment room at will. TB nurses' ideal treatment room should have sufficient ventilation, be more spacious and offer more privacy. The social worker complained that people waiting outside the consultation room could overhear private conversations with her clients.

6.2 Treatment supporter management

The entire South Peninsula area was managed by one TB Care Coordinator, responsible for 9 clinics – including Retreat and Ocean View. Her duties included visiting each clinic, where she counselled TB patients once a month, supported the TB nurse, and managed the treatment supporters.

Soon NGOs will be expected to follow guidelines set up by the Unicity Health directorate if they hope to receive future funding. These will include a definition of a minimal or basic package of services, as well as setting standards for training, treatment supporter role and responsibilities and guidelines for incentives. Even the TB Care Coordinator agreed that TB Care needed to be clear about the roles it wanted the community treatment supporters to play.

The management of the treatment supporters was considered to be very important by the clinic and SPM health management. According to the SPM community health manager, NGOs, such as TB Care, should monitor, support, supervise and follow up with treatment supporters in order for the community DOTS programme to succeed. She believed that they could not work in isolation. A good partnership should be established between clinic and treatment supporter group to enable the supporters to lighten the

workload of the clinic. Only in areas where both the clinic and the community supporter groups are well-managed would community DOTS be useful.

The management of the treatment supporters in both areas was limited due to the restricted time of the TB Care Coordinator. Different concerns were raised by the two clinics. In Retreat, the TB nurse noted that the treatment supporters were not all attending the meetings regularly and that some team building would be necessary. In Ocean View the TB nurse had not yet established a strong relationship with the treatment supporter group or with the NGO. Her concerns were that treatment supporters were not doing a good job.

6.3 Communication

6.3.1 Retreat service providers

Communication between service providers is very important for an effective treatment provision. Relationships between nurses, TB Care Coordinator and treatment supporters in Retreat were generally described as good, even though some role players had a few complaints.

Both the Retreat TB nurse and the treatment supporters described their relationship as very good. The treatment supporters requested her to be TB

nurse again, which she thought was a compliment. She attended their monthly meetings, fundraised with them, and liaised a lot with the group. The communication between treatment supporter and TB nurse was, however, not always smooth. One treatment supporter complained that the TB nurse had not yet brought the tablets for her new patients.

The TB nurse described her working relationship with the other nurses at the Retreat clinic as reasonably good. Since they were short staffed, the nurses were unable to give each other much support.

The communication between TB Care Coordinator, treatment supporters and TB nurse is also very important for the successful management of the community DOTS programme. The Retreat TB nurse seemed to have a good understanding with the TB Care Coordinator, which has been developed over a number of years.

The Retreat treatment supporters saw the TB Care Coordinator about once a month at the meetings and occasionally at their homes. All treatment supporters felt that their relationship with the Coordinator was good, even though she was very busy.

6.3.2 Ocean View service providers

A lack of trust seemed to exist between clinic staff and treatment supporters. There was little communication or teamwork between TB nurse and treatment supporters when it came to planning events or fundraising. Often events would be planned in secret and kept it from the clinic staff. This would lead to, for example, two Christmas celebrations for the TB patients or the TB Day event being held in the absence of the treatment supporters because there was no communication between clinic and TB Care. Even the relationship between the Coordinator and the TB nurse was at times strained. This was evident in the faith that the TB nurse seemed to have lost because the Coordinator did not manage the treatment support group sufficiently. For example, the Coordinator and the treatment supporters were assigned to map the TB cases for the TB nurse. This did not happen, adding to the nurse's perception that the treatment supporters were unsupportive of her and the clinic.

The Ocean View treatment supporters all spoke highly of the TB nurse and other nurses, even though they have experienced some difficulties. They also had good relations with the other nurses.

TB patients were only sent out for community supervision 1½ years after the launch of the treatment supporter group. The reasons – given by the TB nurse - for this delay included that patients had complained about the way

they were being treated by some treatment supporters and wanted to return to the clinic for their treatment. This concerned the TB nurse, since she did not trust that the supporters were doing a good job and only weakening the relationship she had already built up with the patients. This lack of trust could be explained by the poor communication between role players and understanding of their roles.

The treatment supporters perceived this lack in trust as the TB nurse being overly protective of "her patients".

The relationship between treatment supporters and the TB Care Coordinator was very similar in both areas. As in Retreat, the Coordinator was perceived as very busy with other areas and other work. The treatment supporters also only saw her when they had meetings – once or twice a month. She had not monitored them through home visits recently. One supporter felt that there was too much pressure on herself to run and organise meetings sometimes.

The Retreat treatment supporters within the group have known each other for 6-7 years. There was some rivalry between a few supporters and little team work. The treatment supporter meetings were generally not well attended by all members. This created some animosity between those treatment supporters who did attend the meetings regularly and on time, and those who did not.

Even though the individuals had been very good treatment supporters, it has been difficult for the Coordinator to encourage team spirit when some members did not understand the necessity of group meetings and group efforts, such as organising events or fundraising.

The treatment supporters in Ocean View strongly identified with their group and were very committed to working together to organise events and fundraise as a group – besides supervising patients within the community. There was some animosity – especially between two treatment supporters as a result of an apparent breach in confidentiality, which was resolved. This strong sense of group belonging did, however, also add to the "us" and "them" split and rivalry between clinic staff and community treatment supporters.

6.3.3 Retreat and Ocean View clinics

The SPM community health manager encouraged clinic staff to communicate with each other and to share their experiences. At monthly meetings with the districts, the clinic managers shared their challenges and successes. This allowed the clinic staff to hear from others how they managed to increase the cure rate. They then could adapt it to their own strategy – as, for example, the Ocean View clinic did. They encouraged communication between clinics – especially between stronger and less successful clinics – allowed clinics to feel supported and opened them up to other possibilities to fighting TB.

The communication sharing extended beyond the SPM boundaries to the Metropolitan level. The process introduced by the SPM had also been started in other districts with similar successes.

6.4 Incentives

6.4.1 Incentives to TB patients

TB Care handed out food vouchers to TB patients in need. At the time of this study, TB Care was in financial difficulty with available funding for the food vouchers being reduced from R 30 000 to R 13 000. As a result, the NGO had to introduce very strict selection criteria.

The challenge for TB Care was to find a balance between welfare and development. The TB Care Coordinator noticed that when she no longer was able to hand out food vouchers, the number of people who wanted to see her (as social worker) dropped dramatically. She also was aware that she needed incentives for groups work, otherwise patients would not attend her sessions.

The food vouchers were assumed to encourage treatment compliance. Even though the vouchers were for relatively small amounts of money, they were greatly appreciated by very poor patients. It was not possible for the NGO to regularly offer and sustain such initiatives.

6.4.2 Incentives for Treatment Supporters

Besides the TB patients' incentives, money was also extended as a thank you to treatment supporters.

Even though TB Care recruited supporters on the basis that they would work as volunteers, the incentive paid to them was considered by many members as a life support. Of the R30 paid for every patient per month, R20 was paid by the NGO and the other R10 was funded by the health department. The NGO was also for a few months unable to pay the incentives for treatment supporters.

Most of the treatment supporters in both areas were very religious with a strong faith in God, had a supportive family or were retired and lived off their pensions Some did, however, live under the same socio-economic circumstances as their clients – faced with poverty, abuse and unemployment. The temptation could be great to take on far too many patients, affecting the quality of their relationship. This temptation was made greater because of the seemingly poor record systems of both the clinics and the NGO, which did not accurately reflect the number of patients each treatment supporter supervised.

6.4.3 Incentives for clinic staff

The SPM community health management only recently recognised the need for incentives to encourage the nursing staff. Small tokens of appreciation were given to the clinic with the highest cure and completion rates or to clinics that had made great progress. These tokens were for both the clinic team and the individual TB nurse. Nurses welcomed the introduction of incentives and perceived them as a form of recognition for their hard work.

Incentives were considered very important by the SPM community health manager because motivation is especially difficult for the TB nurse. According to the manager, nurses easily lose track of cause and effect when it comes to TB control. It takes at least 9 months before any difference can be seen in the cure or completion rates.

Even though the SPM health manager did not believe that there was enough political support for the fight against TB, she did try to involve more political figure heads, such as the mayor and the ward councillors.

Another problem the SPM community health manager identified in other areas was that the managers tended to take the credit for the clinics hard work.

6.5. Monitoring Systems

6.5.1 Clinic Staff

According to the South Peninsula community health manager, the clinic staff needed to understand the existing monitoring and evaluation system. Previously they were geared to passing on information instead of using it as a management tool. Clinic staff would collect information, send it off for analysis and receive feedback, too late to in order inform management decisions on service delivery.

One common complaint from nurses at both clinics is that they are overburdened with paperwork. *"It's a lot of work and I struggle sometimes. From now on I will not help out elsewhere – now I will only chase after clients and hope to see a difference." – TB nurse, Retreat.* The management explained that the reason for the complicated administration systems was that it was devised at national level.

Despite the many forms, the nurses argued that these forms were too simplistic and did not accurately reflect the work of a TB nurse.

The community health manager adjusted the system, making it simpler and more useful for the clinic staff. Even though all the other paperwork still had to be collected, it was quickly sent on to national level and simply forgotten. Only statistics of interest (cure and completion rates) were considered important.

The SPM trained clinic staff on how to understand and learn how to monitor the cure rates themselves. The Ocean View TB nurse explained that the great improvement in compliance was partly due to her understanding of the monitoring and evaluation systems, which allowed her to reflect on their service delivery and make practical changes.

Even though the Ocean View staff recognised the value of having learnt the monitoring systems, the Retreat nurses believed that it was a duplication of work, which they could do without.

6.5.2 Treatment supporters

The TB Care Coordinator's responsibilities include unexpected spot checks of treatment supporters' work. These spot checks did not happen very often throughout the study, because the Coordinator had very little time. She monitored and gave the treatment supporters in Retreat and in Ocean View feedback at the monthly treatment supporter meetings. This monitoring was

limited to occasionally checking the signed white envelopes and asking about whether the supporters had any problems.

One indicator used by TB Care is the number of cured patients using community based DOTS. It was, however, unclear how such numbers could be verified by the NGO or by the clinic, neither of whom seemed to have adequate records[6].

The SPM community health manager complained that most NGOs did not have clear performance indicators. Most were describing their performance according to the level of inputs instead of focusing on impact.

6.5.3 DOTS

As part of the DOTS strategy, a patient's standardised, short-course chemotherapy treatment should be directly observed under proper management conditions. Treatment supporters and clinic staff are trained to observe their patients when they take their medication. This aspect of the DOTS strategy was, however, not strictly adhered to by the nurses or all of the treatment supporters .

[6] See Appendix B for a proposed monitoring system for community-based TB treatment

The different approaches to DOTS and direct observation may cause confusion – amongst treatment supporters and amongst patients.

The SPM community health manager, however, perceived the handing out of pills without direct observation as an opportunity for service providers to build a relationship based on trust between them.

6.6 Healthy Cities project

The Healthy Cities project only had the broad Healthy Cities vision in place at the time of this study and no specific vision defined for Ocean View yet. The project had also not yet set goals and objectives. The Coordinator planned to base them on the community health survey results.

At the time of the study, the Healthy Cities project was still in the process of encouraging community participation, which was considered one of its important objectives. Nevertheless, this objective was not broken down into indicators. Its vision and aims were not yet drawn up, leaving it unable to monitor its own progress.

One limitation of the project was its threadbare budget. *"We're literally living off crumbs." – Healthy Cities Coordinator.* The project was relying heavily on

the cooperation and participation of other departments to address Healthy City concerns. This made funding of projects very difficult.

Cooperation with other departments is a relatively new concept, which was formalised with the introduction of the Integrated Development Planning legislation. This legislation stipulates that the various directorates of a municipality should coordinate their efforts around service delivery and development of a community. This change of approach to planning and implementation has been difficult for the local government. According to the Health Cities Coordinator, the departments were still stuck in their old ways of thinking according to silos, instead of across directorates. Two years ago, the Coordinator presented a workshop about Healthy Cities to the officials, highlighting the holistic nature of health. Environmental management, waste management, community development, community health, environmental health, and housing management (even though reluctantly) agreed to support the project. However, when it came to assisting with initiatives, the officials were reluctant to work together.

Combined with the limited budget and involvement of departments, the Coordinator complained that he lacked the authority to encourage departments to commit to the process.

To add to the project's challenges there seemed to be political infighting and confusion about the United Nations' Agenda 21[7] initiative, which is driven by the urban planning division. The Agenda 21 is a very similar concept to that of the WHO's Healthy Cities.

The Agenda 21 should, however, be understood as a wider concept within which Healthy Cities is a framework that can be used to achieve the Agenda 21's overall objective of sustainable development and health. The Coordinator perceived the Agenda 21 as competition, especially because, since it was urban planning driven, it received a much bigger budget. *"I think that the*

The Health directorate, which was always operating on a fairly tight budget - relying on subsidies from Province the project could not compete with Agenda 21. Since it has a greater budget, Agenda 21 also seemed to have more political clout than the Healthy Cities project.

[7] Agenda 21- the global action plan – was started at the United Nations Conference on Environment and Development in 1992. It is committed within sustainable development to protect and promote human health. *"Human beings are at he center of the concerns for sustainable development and are entitled to a healthy and productive life in harmony with nature."* It recognises the need to address problems at a local level and sees Healthy Cities as a mechanism to address these concerns (Schirnding, et al., 1999)

CHAPTER FIVE
Discussion

This study targeted clinics with high cure rates to explore their success from both the service providers' and clients' perspective. These impressions were compared to the comprehensive Primary Health Care's (PHC) and Healthy Cities' concepts of the principles of equity, community participation and a comprehensive approach to health care. Theory presents that through the implementation of these principles, enabling environments could be created. These environments could help find long-term solutions for the fight against TB.

1. Limitations of the Study

As discussed in chapter two, the challenges of putting research into practice were varied. The unexpected bureaucracies, gang related violence, and the suspicion of the participants were part of the evolution of the study. With a new framework and with proper buy in from all stakeholders, the study was able to continue.

The selection criteria of participants had to be changed and widened by including both new and re-treatment TB patients to allow for a larger sample, considering that both of the clinics had a relatively small number of pulmonary TB patients.

As mentioned in chapter three, the TB patients' selection was biased since those persons attending either treatment service, were also more likely to be compliant and therefore more favourable towards the treatment delivery. Both clinics did, however, have high compliance and cure rates, with the majority of patients adhering to the treatments. Due to the difficulty of locating and convincing non-adherent patients to participate in this study, these patients were underrepresented. This bias was taken into consideration during analysis and the perceptions were considered to reflect mostly compliant patients' experiences of their environment and of their treatment.

Some may argue that one of the limitations of this study was its reliance on subjective perceptions. The lack of a large, randomly selected sample means that these findings cannot be generalised. These perceptions, nevertheless, provided a glimpse into the lives of both TB patient and service provider and into some of the complexities involved in delivering clinic-based and community-based anti-tuberculosis treatments in Retreat and Ocean View. It also reflected the researchers' perspective in the choice of theoretical framework.

Where possible, however, the subjective data was presented with statistics provided by Statistica SA as well as with other research findings.

Even though these findings are not generalisable, it can be assumed that some of the challenges and successes are applicable to other areas, clinics, and TB NGOs. They may be able to learn from these two 'success stories', as well as reflect on these successes within the different framework of comprehensive PHC and the Healthy Cities concept. This descriptive study is a form of information and experience sharing that may encourage different thinking.

2. Main Findings and Conclusions

The incidence of TB in South Africa is expected to rise dramatically by 2005 – with an estimated annual caseload to be in excess of 600 000, of which 400 000 cases would be directly attributable to HIV infection (MRC, 2000). These figures highlight the importance of utilising resources effectively – drawing on untapped resources in the community and combining efforts to create healthy communities.

2.1 Social Context

Chapter one discussed the importance of the social environment in determining the health status of a community. It also argued for the close link between health and development. Chapter four presented the descriptions of the environment and social context of Retreat and Ocean View from the service providers' and tuberculosis patients' perspective. Neither the level of education nor the nutrition of the majority of TB patients interviewed was very

conducive to healthy choices. Combined with the predominately poor living conditions (lack of housing and overcrowding, prison conditions), high levels of alcohol and substance abuse and unemployment, and the participants' concern for their safety, most patients were faced with a variety of environmental factors that determine ill health. It is assumed that this "disabling" environment - especially the one in Ocean View - may explain the high numbers of re-treatment TB patients (52%) who had previously been cured from the disease. Even though their social context did not seem to have a major impact on participants' overall compliance[7], it can be assumed that these factors nevertheless impacted on their health and on their chances of contracting the disease a second or third time.

According to the descriptions of both the service providers and the patients themselves, development should address the underlying causes of ill health and tuberculosis if the community is to rid itself of the disease for good.

2.2 Perceptions of Tuberculosis and Compliance

Participants, who were compliant, considered their own health to be a high priority. This attitude seemed very important in motivating patients to come to the community-based, as well as to the clinic-based treatments. Besides

[7] It must be considered that most of the participants in this study were compliant and non-compliant patients were underrepresented.

building strong relationship with their patients, the service providers felt that they had no control over the patients' attitudes.

The perceptions of both patients and service providers in this descriptive study reflect the findings of other research, highlighting the importance of the patients' health beliefs (Dick et al., 1996; Barnhoorn & Adriaanse, 1992; Conrad, 1985), patient – service provider relationship (Morisky et al., 1990; Barnhoorn & Adriaanse, 1992; Dick et al. 1996; Squier, 1990), access (Thomson & Mydral, 1986), alcoholism and homelessness (Fullimore et al., 1993) and socio-economic factors (Mechanic, 1992) in determining compliance. These perceptions also highlight that compliance is not determined by one factor alone, but should be understood within the context of the patients' lives.

Compliance could be supported or made easier for patients within an enabling environment. Local economic development, education, and housing, as well as addressing the conditions of prisons, should also be priorities in controlling TB.

2.3 High cure rates and the success of the South Peninsula

Since its introduction of a more focused approach to TB control, the South Peninsula district has achieved high tuberculosis cure rates throughout the year. The average cure rate in the district for last year was 83% - very

close to the target set by the WHO of 85%. Their approach seems to be successful in terms of increasing cure rates.

The new approach taken by the community health management focused the clinic staff's attention on only *new* smear positive tuberculosis patients and on completed cases (see chapter 4: Health Care Management). With this approach the emphasis was no longer on the seemingly unachievable (preventing non-compliance). This focus seemed to have a positive impact on reducing treatment non-compliance and increasing cure rates.

Other factors that seemed to have contributed to the success and high cure rates of the Retreat and Ocean View clinics included the very good, personal and ongoing relationships between patients and the respective TB nurse. The treatment was accessible and convenient at both clinics. The TB nurse was able to offer the patient alternatives to supervision at the clinic – such as community-based treatment.

The collaboration between the Retreat TB nurse and treatment supporters seemed to have lightened the clinic's workload, freeing up her time for administrative duties, as well as having an impact on the quality of the interaction between patients and health workers.

In Retreat, the treatment supporters have been assisting the TB nurse for several years and have established a level of trust. The Ocean View treatment supporter group, however, was formed only recently, with several concerns that still needed to be resolved, such as communication and strategic selection of community members to be trained as treatment supporters.

Both TB nurses and treatment supporters were flexible about the DOTS 'direct supervision' rule by giving a few days supply of medication to patients they believed to be reliable. Even though this may seem to jeapordise the patient's compliance, the gesture may contribute to relationship and trust building between service provider and patient. It was a risk but the patients were generally grateful for such understanding and did not seem to want to disappoint the nurse or supporter by interrupting their treatment.

Another reason why the two clinics may have achieved high cure rates is the passion and dedication of the TB nurses. The management recently introduced incentives to recognise the hard work of clinic staff. They also promoted the involvement of councillors and public officials to attend ceremonies where certificates were presented.

The management furthermore encouraged communication between clinics to allow them to share their experiences – successes and challenges. This

allowed clinics, such as Ocean View, to learn from the Retreat clinic about how to tackle TB treatment.

2.4 Cure rates and comprehensive Primary Health Care

It is going to take more than drawing on community resources and high cure rates to deal with the anticipated TB crisis. The focus of the TB control programme in the South Peninsula district has been primarily on crisis management and on successfully curing the infected TB patients first time round. This approach did not recognise the underlying social causes of ill health – including tuberculosis. Cured patients returned to the same social contexts that gave rise to the illness in the first place. Even though compliance was important for the cure and treatment success, it cannot prevent a second or third tuberculosis infection.

The PHC principles - equity, community participation, and comprehensive and intersectoral approach to the provision of health care - aim to address the underlying causes of ill health as well as providing efficient treatment for multiple infections. This descriptive study explored the success of these two clinics within this framework.

2.5 *Primary Health Care and clinic-based treatments*

2.5.1 *Community Participation*

According to the clinics, community participation was achieved by involving community treatment supporters as volunteers in delivering health services.

The clinics did not seem to actively promote community participation in forums (Health Committee) or in clinic activities (food garden). The majority of participants had no knowledge of the food garden or when and where the Health Committee meetings were held. This may be due to the clinic staff's perception of the community (both Retreat and Ocean View) as dependent and lacking initiative. Perhaps this perception created a feeling amongst service providers that encouraging participation would be a waste of time because the patients never have shown interest before. It may also be that the clinic staff believed that it was not their responsibility to empower the community.

Socio-economic hardships, as well as the different levels of education and empowerment, have been found to limit community participation (Dennill et al., 1997; Matthews, 1992). Combined with the high levels of crime in both Retreat and Ocean View, the reluctance of residents to organise themselves for community meetings was understandable.

With low social capital, residents can only draw on limited social resources that can exert social pressure over its members to establish norms that encourage social responsibility and healthy choices (Butchart & Emmertt, 2000). The success of community participation is linked to the strengthening of social capital and to addressing wider community issues through development. It seems to like a vicious circle: addressing wider community problems requires community participation, however, these social problems contribute to limiting the involvement of the community.

Even though there was a functioning Health Committee in Retreat, it did not have a strong community representation and was more focused on resolving the daily practical delivery problems than on offering the community a forum for decision-making, which could bring about change.

The clinics fell short in achieving the objective implied by the community participation principle, which is to promote community self-reliance and involvement in planning, organising, operating and controlling of the health care services.

2.5.2 *Equity*

The anti-tuberculosis treatment at both Retreat and Ocean View clinics were accessible and available to all TB patients. Findings suggest that health care workers who implement a successful treatment programme need to have a certain level of respect from the community, which is difficult to achieve (Wilkinson, 1997; Dick et al., 1997). The clinic staff in general, and the TB nurses in particular, had good ongoing relationships with their clients and were respected by the participants. All respondents spoke very highly of the TB nurses – especially of the Ocean View TB nurse – and felt welcome at the clinic. A few patients complained about a couple of nurses in the Retreat clinic, who did not seem friendly and approachable.

For those who were finding it difficult to attend the clinic for their medication, the TB nurse would give the patients the option of either community or workplace DOTS. This systems was working well in Retreat, where community supervision has been in place for several years. In Ocean View, however, patients were only placed with treatment supporters recently. Some patients who were unable to attend the clinic for their medication and who were judged as "reliable", were given several days worth of medication at a time.

Staff shortages did, however, prevent the TB nurses at both clinics to regularly follow up with those patients, who had interrupted their treatment. The Retreat clinic also had a problem with delivering the necessary drugs to the treatment supporters, which had serious implications for equity and compliance.

The 'narrow' definition of equity seemed to have been achieved by both clinics. The broader understanding of the principle, however, implies more than accessibility, availability and affordability. It also implies addressing other inequalities, such as the causes of poverty as part of preventing health problems. This implies that the clinics should encourage the community to take ownership and responsibility for their own health. In terms of this understanding, the community health management chose to focus on curative, rather than preventative actions.

2.5.3 Comprehensive Approach to the provision of health care

The TB clinics were very task oriented – their main objective being to increase the TB cure rates. The primary health care principle of comprehensive approach, however, implies that clinics are also obliged to address the underlying causes of ill health, including preventative services. This would imply that a TB nurse could use the contact with the TB patient as an opportunity, for example, to address other health issues - moving away from disease-specific treatments. It also means that clinics

should be involved in other activities which promote health. The treatment was generally disease-specific, with only the occasional interaction with a patient addressing other health concerns, such as family planning and HIV. Opportunities for such interaction were not used to their fullest.

Substance abuse is widespread in South Africa's metropolitan areas and is a major contributor to treatment interruption (Dick, 2001; WHO/CDC/USAID, 1998). It was, however, not addressed by the clinics, who relied on the TB Care Coordinator to counsel the patients.

Neither TB nurses passed on relevant information of organisations to patients, who may have required some assistance. This was less relevant in Ocean View, where there was only a very limited number of active developmental organisations. Patients were also not sufficiently informed about the Health Committee meetings or about the food garden.

Building partnerships with such organisations and a proper communication strategy may not only improve community participation, but also help shift their service delivery towards a more comprehensive approach.

The provision of nutrition was perceived within the welfare framework. The food garden was a step toward a more developmental approach. The breakfast club and other donations for patients were considered to be

important for compliance. However, these incentives seemed difficult to sustain on a regular basis. It seems that it will no longer be enough to find and distribute food donations and that education may be one long-term solution.

The Ocean View clinic was involved in raising the awareness of students at their local High School around health issues. Both clinics organised events on World TB Day. Nevertheless, the TB nurses recognised that they were focusing more on curative and disease specific treatments than on preventative action. This was partly due to the SPM management's direction, as well as to the lack of staff at both clinics.

Even though the SPM management recognised the importance of such a comprehensive approach, their first priority was the control the current TB crisis in the Western Cape. Such preventative, multi-sectoral action was considered to be possible through the Healthy Cities' projects.

Both clinics were implementing selective primary health care, which emphasises curative activities, rather than preventative ones. This approach has been criticised for not taking responsibility for the underlying causes of ill health, as well as reinforcing the authority of health professionals through its neglect of community participation (Williams, 1992).

2.5.4 *Overview of Clinic-based supervision*

	Retreat		Ocean View	
	Strengths	**Challenges**	**Strengths**	**Challenges**
Community participation	❑ Functioning Health Committee	❑ Health Committee's focus only on service provision, instead of wider community health concerns ❑ Community representation at the Health Committee limited ❑ Poor community participation in food garden		❑ No Health Committee ❑ No food garden
Equity	❑ Good and long standing relationship with treatment supporters and TB Care – good cooperation ❑ TB nurse made the treatment more accessible by giving some patients more than one dose of medication per visit	❑ A few complaints about some of the clinic staff ❑ Difficulties with drug availability and disbursement to the treatment supporters ❑ Did not address the underlying causes of inequality and ill health	❑ TB nurse made the treatment more accessible by giving some patients more than one dose of medication per visit	❑ Did not address the underlying causes of inequality and ill health ❑ Difficulties with the introduction of treatment supporters: ▪ Most treatment supporters lived in the same area (limiting their use in other areas where TB was a problem) ▪ No trust in treatment supporters' abilities ▪ Poor cooperation ▪ Reluctance of TB nurse to make use of treatment supporters (limiting the treatment's accessibility)

	Strengths	Challenges	Strengths	Challenges
Comprehensive approach	❑ Food garden (step toward developmental approach to provision of nutrition) ❑ Regular breakfast club and other donations	❑ Provision of nutrition perceived within the welfare framework ❑ Time consuming to sustain the breakfast club		❑ Food garden put on hold ❑ Provision of nutrition perceived within the welfare framework ❑ Irregular breakfast club ❑ Difficult to sustain the breakfast club
Health Care Management	❑ Dedicated TB nurse (no rotation of duties)	❑ Little team work and support for the nurses ❑ Staff shortages ❑ Poor records of community-based treatment ❑ Understanding and working out statistics by themselves was perceived as duplication ❑ Overburdened with administrative work	❑ Very dedicated TB nurse and staff ❑ Good team work and support for each other ❑ Understanding the statistics provided insight and was used as management tool	❑ Staff shortages ❑ TB nurse has dual role (clinic manager as well) ❑ Clinic too small ❑ Poor records of community-based treatment ❑ Overburdened with administrative work

The main strength of the Retreat clinic was that there was a good partnership between its dedicated TB nurse and the treatment supporters. This was not the case in Ocean View, where the TB nurse relied on the good team work and support for her colleagues to achieve such high cure rates. Both clinics fell short of achieving the kind of community participation, equity and comprehensive approaches referred to in the comprehensive PHC.

2.6 *Primary Health Care and community-based treatment*

2.6.1 *Community Participation*

The recruitment of treatment supporters was based on very wide selection criteria. TB Care's objective was to empower as many community members as possible, instead of necessarily focusing on the clinic's goal of targeting specific areas where there was a high TB incidence. Considering the large numbers of inactive treatment supporters in the Western Cape and the limited resources available (time and money), this strategy seemed unsustainable. The NGO cannot aim to generally empower a community, without either setting itself up for failure or appearing to be waste resources.

In Ocean View one problem was as a result of this broad empowerment strategy. Too many community members from the same "suburb" were trained, instead of ensuring that treatment supporters were evenly spread throughout Ocean View, and therefore equally accessible for community-based treatment.

Community participation was generally understood within the health services model, in which it is understood as the mobilisation of people actively to take part in the delivery of health services. The Retreat

treatment supporter group acted as such an extension of the clinic's work. The Ocean View supporter group, nevertheless, extended its participation beyond their duties with the clinic and TB Care to other projects, such as the Healthy Cities activities.

Within TB Care, community participation was understood more within the community development definition, whereby the treatment supporters were actively involved in the planning, organising, and operating of the community DOTS service – more successfully in Ocean View than in Retreat. As part of the management body of TB Care, the treatment supporter representative was able to influence the decisions concerning their organisation. Since the Retreat supporters did not meet regularly or perceive themselves as part of a group, they did not benefit from or participate fully in these structures. The treatment supporters also did not attend Health Committees, where they would be able to make decisions concerning the clinics.

Community participation is considered by Arnstein (1969, in Matthews, 1992, pg. 102) to be an "empty ritual", unless the community is able to make decisions about how resources are allocated.

2.6.2 *Equity*

Through community-based supervision, the anti-tuberculosis treatment was more convenient and accessible to patients who chose this option over the clinic-based treatment. The service bridges the gap between clinic and patient since the treatment supporters were from the patient's neighbourhood. Only in Ocean View were there a few problems with regard to the selection of the treatment supporters - most of whom lived in the same area - which did not give every patient the same opportunity for convenient treatment service.

As with the clinics, the community-based treatment did not embrace the comprehensive understanding of equity. Through the Healthy Cities project in Ocean View, this definition of the principle may be achievable. The treatment supporters were starting to expand their involvement to cleaning campaigns. TB Care had unfortunately not been invited to take part in the Healthy Cities process – a partnership which could have allowed the NGO to start to address the underlying causes of ill health in Ocean View.

As mentioned in chapter one, inequality is caused by various factors – including social and economic structures and centralised decision-making. Only combined with community participation and a comprehensive, multi-

sectoral approach to addressing health issues, can true equity be achieved by the health services.

2.6.3 Comprehensive Approach to the provision of health care

With resources becoming scarce, the call to utilise the untapped resources within communities becomes more urgent. With it comes the recognition that it is no longer efficient to offer disease specific treatments.

TB Care recognised the need to expand their supporters' knowledge and services to include HIV and nutrition. The Ocean View group was still waiting to receive their training from the NGO. Treatment supporters seem to becoming more and more like community health workers (CHWs), who are also trained in the care of under five year olds and pregnant mothers, prevention of common illnesses, first aid, and environmental health. The community-based treatment - like the clinics - understood the provision of nutrition more within the welfare paradigm. All of the treatment supporters were generous in giving patients food, however, there was no clear fundraising or development strategy in place to coordinate efforts between them – particularly for the Retreat group. Such a strategy would take the individual sense of responsibility from the treatment supporter (most of whom were paying out of their own pocket) and allow them to work as a group and extend their reach. The Ocean View group was more

focused and planned several fundraising events, however, their efforts and those of the clinic were not coordinated. TB Care did not have any strong partnerships with other organisations or government departments from which the community-based treatment could have benefited. Such possible partnerships include working together with NGOs that deal with substance abuse or offer skills training for community members, and with the Healthy Cities project.

2.6.4 *Overview of Community-based treatment*

	Retreat		Ocean View	
	Strengths	**Challenges**	**Strengths**	**Challenges**
Community participation	❑ Responsible for their own funding and bank account ❑ Active volunteers for other organisations ❑ Represented at the TB Care management decision-making body	❑ The group still seemed to be more of an extension of the clinic's services	❑ Responsible for their own funding and bank account ❑ Active group within other organisations ❑ Aware of community events and meetings ❑ Represented at the TB Care management decision-making body	
Equity	❑ Very good relationships with their clients ❑ Able to give more personalised, convenient service	❑ Confusion about DOTS ❑ Did not address underlying causes of inequality and ill health	❑ Very good relationships with their clients ❑ Able to give more personalised, convenient service ❑ Started to address some of the underlying causes of ill health through the Healthy Cities project	❑ Poor communication and cooperation with clinic ❑ Most treatment supporters lived in the same area – limiting access to community-based treatment ❑ Confusion about DOTS
Comprehensive approach	❑ Trained in HIV/AIDS and nutrition ❑ Most treatment supporters had a background in other related issues (home care, First Aid, counselling) and able to give more diverse service	❑ No visible partnerships with other organisations or strong relationships with government departments	❑ Treatment supporter group involved in other health related activities, such as Healthy Cities cleaning campaign ❑ Most treatment supporters had a background in other related issues (home care, First Aid, counselling) and able to give more diverse service	❑ No visible partnerships with other organisations (such as AA) or strong relationships with government departments ❑ Not yet trained in other health issues, such as HIV/AIDS or nutrition

	Strengths	Challenges	Strengths	Challenges
Health Care Management	❑ Very good relationship with TB nurse	❑ Poor attendance of meetings ❑ Little team work ❑ Insufficient monitoring by TB Care coordinator ❑ Incentives for patients and treatment supporters difficult to sustain ❑ TB NGOs will need to provide a more standardised service package in the future with clear roles	❑ Good team work	❑ Initial personality clashes within treatment supporter group ❑ Poor communication with TB nurse ❑ Insufficient monitoring by TB Care coordinator ❑ Incentives for patients and treatment supporters difficult to sustain ❑ TB NGOs will need to provide a more standardised service package in the future with clear roles

Within their organisation, the treatment supporters' level of community participation was close to the developmental interpretation of this principle, even though the Retreat group continued to act more like an extension of the health service. Their service made the TB treatment more convenient than the clinic-based option. Only in Ocean View was this option less equitable than in Retreat, due to, for example, the poor cooperation with the clinic. The training in other health related issues allowed them to offer a more holistic service. The Ocean View group seemed to move beyond the disease-specific treatment and were involved in other wider community health activities.

2.7 Healthy Cities project

As mentioned in chapter one, the Healthy Cities principles embrace the positive understanding of health, highlighting the need to develop and strengthen existing resources and social capital. It also understands the three principles of PHC as ultimately addressing the inequalities within communities – social and economic – through community participation and comprehensive and multi-sectoral partnerships. This study explored the progress and challenges faced by the Healthy Cities project in Ocean View.

2.7.1 Community Participation

The project had only achieved limited community participation in the 18 months since its inception and was only in its early stages. Methods of informing and consulting the community about meetings and of sustaining their interests would need to be looked at. Most importantly the Healthy Cities project would have to deliver on its promises and keep the community interested. Even a treatment supporter from Ocean View had become disheartened about the lack of progress the Healthy Cities project seemed to be making and susequently no longer attended the Healthy Cities meetings.

The project, did, however offer the treatment supporter group an opportunity to become involved in wider community health issues, outside the TB framework. This opened them up to understanding that health is holistic and that a more comprehensive approach is required to achieve a healthy community.

The Health Cities project coordinator considered the process of achieving community participation, as more important than the impact of its initiatives. This was based on the overall aim of the project to empower the community to ultimately take ownership of the project and take responsibility for their own health.

2.7.2 *Equity*

Even though the project has implemented, some of its diverse initiatives which addressed environmental health and local economic development issues, the lack of a vision and mission specific to the Ocean View community gave the impression that the project was addressing inequalities in a haphazard manner.

2.7.3 *Comprehensive Approach to the provision of health care*

The project is based on the assumption that comprehensive and multi-sectoral action is necessary to achieve its goals. Even though the Healthy Cities project has the potential of achieving the third principle of a

comprehensive and coordinated approach to health service provision, the project was faced with many different challenges. The Healthy Cities project had only made limited progress since its inception. Besides the poor community participation, it had to tackle organisational culture issues, such as poor cooperation between departments. One major obstacle that threatened its success and continued existence, was the limited political commitment to the Healthy Cities concept in terms of budget allocation and authority. Without these the coordinator was dependent on the good will of other departments – which is not a very encouraging strategy.

2.8 Clinic-based treatment compared to community-based treatment

Both clinics had achieved high cure rates. For the Retreat clinic this could be ascribed to the hard work and dedication of the TB nurse, as well as the functional community-based treatment, which offered patients a more convenient and accessible supervision option. Considering the large case load, this support freed the TB nurse's time up for administrative work and fundraising, as well as allowing her to provide a better clinic-based service.

As in Retreat, the Ocean View TB nurse was very dedicated. Due to the difficulties already mentioned above, the community-based treatment was not considered supportive. Instead she relied on the good team work and support of the other clinic staff to ensure high cure rates.

The success in terms of cure rates for the community-based treatment was difficult to judge, since all challenging and non-compliant patients are sent back to the clinic-based treatment. All community-based supervision achieves, therefore, a 100% cure and completion rate. Neither the clinic nor the NGO had means of measuring the impact of community-based treatments.

When measured against the 3 PHC principles, both clinics rated similarly. The Retreat clinic seemed to have higher – even though limited - community participation than the one in Ocean View. Within the community-based project, a more developmental approach was being introduced. Community treatment supporters were able to make decisions concerning their organisation and had control over their groups' finances. The Retreat group did, however, seem more stuck in the health care definition of being an extension of the clinics' service.

Both clinic-based and community-based supervision offered very accessible and convenient treatment. The relationships between TB

patients and TB nurses and treatment supporters were very good and improved accessibilty. The difficulties with the introduction of the Ocean View treatment supporters, however, limited equity in that area. Neither the clinic- nor the community-based treatments addressed the underlying inequalities of their communities.

Considering that their focus was mainly on curative functions, neither clinic achieved a truly comprehensive approach to health care. The introduction of the food garden in Retreat and the interaction of the Ocean View clinic with its schools and with the Healthy Cities project, were signs of their recognition of the importance of development and education.

The community-based treatment allowed for more time with each patient. With their training in other related health concerns, the treatment supporters were able to offer patients a more comprehensive service. Neither the clinics, nor the NGO had any partnerships with government departments or other organisations, which could have helped them to address TB in a more holistic manner.

Clinic- and community-based treatment should be considered by all role players as a partnership. Only when each aspect is well managed and when all roles are clear, can the combination achieve the success of high

cure rates. Poor supervision and monitoring of the treatment supporters and poor communication may have contributed to the lack of trust the Ocean View TB nurse had concerning the supporters' skills. This could have easily jepordised the success of the community-based treatment in Ocean View.

The community-based service - rather than the clinic-based treatment - seemed to have started shifting towards a more comprehensive approach of the PHC. TB Care acknowledged the need to give the treatment supporters decision-making powers, to train them in other health issues, as well as encouraging the supporters to get involved in the Healthy Cities project. Within the Healthy Cities framework, both the Ocean View clinic and the Ocean View treatment supporter group were able to start establishing partnerships, which could allow them to embrace comprehensive primary health care.

2.9 Is the comprehensive approach too idealistic?

When compared to the comprehensive PHC principles, instead of the target cure rate of 85% and the curative approach, the two clinics seem less 'successful'. However, as mentioned in chapter one, many would argue that achieving the comprehensive PHC principles is unrealistic and unobtainable (Downie et al., 1997; Matthews, 1992).

The comprehensive PHC and the Healthy Cities approaches assume that outside organisations and particularly other government directorates are not only committed to creating enabling environments, but also accept shared responsibility for the health of the community. These assumptions depend on strong political commitment to social change, as well as restructuring of levels of government that would encourage cooperation between directorates.

The government has recognised the need to utilise its resources more effectively and efficiently by legislating the IDP (Integrated Development Planning) approach for local government. As mentioned in chapters one and four, departments were struggling to move out of a silo pattern form of thinking, which is currently still supported by the budgetary process. The Healthy Cities project is driven by local government, however, it has no authority and depended on the buy-in from other departments to assist it with achieving its objectives and vision. This may not be enough to change the functioning of the local governments.

The comprehensive approach also assumes that there is sufficient social capital in communities to draw on in order, for example, to implement the principle of community participation. As mentioned in chapter four, these resources need to be strengthened and developed.

Despite these challenges, the comprehensive PHC and Healthy Cities approach does not have to be unobtainable. As seen at the Retreat clinic with the

introduction of the food garden, the involvement of the Ocean View clinic in their involvement in raising the awareness of school children around health issues, and the Ocean View treatment supporter group's participation in the cleanup campaign, both the clinics and community-based project were starting to become more involved in comprehensive, preventative activities through the Healthy Cities initiatives.

Despite its many challenges, the Healthy Cities pilot project is valuable in terms of highlighting the fact that each framework needs to first be adapted to our South African context, before it can be expected to achieve its objectives. With a suitable framework, such as the Healthy Cities approach, as well as strong political commitment to such a process, the principles may be achievable. With the pessimistic predictions of future TB and HIV rates, a comprehensive developmental approach seems to be the only logical long-term approach to create enabling environments to rid South Africa from this social disease.

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APPENDICES

APPENDIX A: Observations

APPENDIX B: Monitoring system

APPENDIX C: Instruments

APPENDIX D: Quotes

APPENDIX A
Observations

1. A day at the Retreat clinic
2. A day at the Ocean View clinic
3. A morning with the doctor in the Ocean View consultation room
4. Community-based treatment within the treatment supporters' homes

These observations provide extra information relating to equity issues, which are presented in chapter four.

Observation: A day at the Retreat clinic

The reception is behind a big glass wall with pictures and notices: "Don't knock on window - will attend to you soon." There is a person waiting at reception. He is not acknowledged. He can see into records room where nurses are sitting but cannot make them aware of him (no knocking).

I also feel out of place. People react to my skin colour, see "white" and think I'm the doctor, nurse or a nursing student, greeting me with "Morning, Doctor" or "Morning, Sister."

People are walking in and out of the clinic. A nurse comes to the reception's window with an envelope – but ignores the person for about 10 minutes. He asks her for his TB results and is asked to wait in the waiting room to be weighed.

There are many posters in the reception and inside the clinic. Most of them are about safe sex, condoms and sterilisation. Others include crime fighting/missing children, measles, breastfeeding, TB, and healthy eating. "Don't litter", "Don't smoke", "No eating/drinking in clinic".

There are about 5 TB patients waiting outside the treatment room. 23 mothers are also waiting with their babies. The door to the treatment room is open. There is one chair in the treatment room for the client and one chair and desk for the TB nurse. On top of the desk there are many plastic containers for the TB medication. Patients come in, find their container, swallow their medication and have their cards signed. The treatment room is full of colourful posters, photographs of past workshops and graphs reflecting the clinic's compliance and cure rates. There is also a list of resources up on the wall: soup kitchens, food parcels, doctors, social workers, circumcisions, SANCA, Bellhar psychiatry, AIDS, Alcohol. Hanging on one of the walls is also thank you letter from a patient: August 2000, thanks for the advice and the support.

The TB nurse and the patients only have factual conversations: when were the tablets last taken, who signed the card, the next set of tablets for so and so many weeks. One patient comes into the treatment room at a time: greetings, who are you's. Some patients just come in and drink tablets, without much contact with the TB nurse, except to sign their card and quietly get on with things.

Observation: Retreat clinic continued

... the newly notified patient the length of the treatment, the treatment supporter's name and address, that Wednesdays is breakfast club day at the clinic and that she is welcome to come. She advises the patient not to drink the pills on an empty stomach and that diet is very important: vegetables, fruit, water. She hands out a pamphlet. They together look over the green card. *"Look after it. It's your property – it's international, you can carry it all over the world. So no excuses – if you go away for a short period and if you are reliable, I will give you pills for that period. Otherwise you have to go to a clinic in that area. If you skip one day, it shows me that you are not serious about getting better and that you are not reliable. But you look to me like a reliable person."*

There is no direct observation of how or if patients swallow their pills. One patient is given an injection - behind a closed door in the small room next door. It is 10:30 am and out of 30 patients, only 7 still need to come for their medication. When no one is in the room, the TB nurse refills the containers with the necessary drugs for the next day. A thin patient knocks on the door, walks in and greets. He takes his pills and leaves. The TB nurse continues to fill containers. There is no 'real' conversation and interaction between patients and the nurse. This may be due to my presence. Another patient enters. He is late and apologises. There is little interaction and no eye contact, as the nurse is still filling the containers with drugs. He says that his wife has not come to collect the medication for the children and herself, claiming that the nurse refuses to give them to her. His wife does not want to come and she thinks that the children are a waste of her time. He has come instead to collect them. The nurse denies his wives' claims and gives the pills to him.

"No porridge, Sister? I only had some two weeks ago. Please, Sister." No response. The nurse leaves, without saying anything to the patient. She fetches and gives him the food – *"Thank you, Sister – enjoy you weekend." "You too".*

In reception I can hear someone tapping on the window. It is the nurses' tea break and they simply close the door so that nobody can see into the records room. *"It's unnecessary to knock like that."* There is no sign informing patients about tea breaks and the reception is unmanned at all times.

Once the last patient leaves, the TB nurse packs away the containers and starts with her administrative work.

APPENDIX A

Observation: A day at the Ocean View clinic

It is Wednesday morning and the clinic is full of people – mostly mothers with their babies – sitting everywhere in the hallways and small waiting area. The building is much smaller than the clinic in Retreat. The clinic shares its space with the day hospital. Even though they all have been involved in an integration process, there is little interaction between day hospital staff and clinic staff. They only share the receptionist, who is sitting behind the glass of the small records room. There are also about 15 people waiting in the day hospital waiting room.

Two nurses are working with 5 year olds and younger. There is one doctor to see those patients who could not be assisted by the nurses. Today is family planning, TB and 'baby' day. The TB treatment room is at the end of the clinic/day hospital. The TB nurse (and clinic manager) is rushing up and down the corridor between the TB treatment room and the other three consultation rooms. She greets patients and knows most of them by name.

In the treatment room there is a sink, desk and two chairs. On a small table are all the containers with the patients' medication. There are many posters on the walls about TB, as well as the statistics of the Ocean View clinic and certificates congratulating them on their high compliance and cure rates. The last treatment outcome for the fourth quarter of 1999 is 100%.

The TB nurse sits at her desk chatting with a client next to her. Others walk in and take their medication. There is no direct observation. She sees a patient who is sick again after being previously cured of TB. *"You are sick again because your body is weak. You have been naughty again,"* she reprimands. He smiles and says, *"Yes, sister." "You cannot fool me. If you want to get better you must stop this nonsense."* She asks the patient if he understood everything that the doctor had said, reprimands him again and tells him that his children need to be checked for TB and treated if necessary. A small child walks in and the TB nurse greets her and gives her a packet of powered milk and some porridge.

Patients are usually asked about their health and families. Even though not every patient is greeted, some feel free enough to stop the TB nurse and ask her to have a chat. This is when the TB nurse locks the door of the treatment room and the other patients wait outside the treatment room on benches.

APPENDIX A

Observation: Ocean View clinic continued

...The TB nurse has to attend a meeting and asks the caretaker to oversee the DOTS. He sits at her desk and is busy listing all the cured people in the register. The caretaker is a well-known man in the Ocean View community and member of several forums. A patient comes in and greets. He cannot find his container and asks the caretaker if he knows what medication he should take. The caretaker sends him to the other nurses. Once his tablets are sorted out he takes two of the containers with him for his friends who are also TB patients. The TB nurse returns later in the morning form her meeting and sees to her other duties, such as administration, home visits and attending the monthly treatment supporter meetings.

Observation: A morning with the doctor in the Ocean View consultation room

The first TB patient enters and sits down next to the desk at which the doctor is sitting. *"How are you feeling? Any improvement?"* He complains of a rash – a side effect of the treatment - and that he is eating but still loosing more weight. The doctor explains his test results – about sputum and x-rays. They both look at his x-rays, comparing the two images. She tells him about the necessary drug change - not really explaining. She does not examine him before referring him to the TB nurse for new pills.

The second patient is a TB treatment defaulter. He stopped his treatment last year. The reason he gives to the doctor is that he had to follow a job and needed the money. *"BUT you should have spoken to the clinic and could have asked your employer to do DOTS – no excuse."* He will be hospitalised for 8 months. *"You must finish this treatment or you'll die."* The patient is aware of the need to hospitalisation and agrees to it [which the doctor says is unusual]. He is starts telling her about his new job but she interrupts him and the conversation is not picked up again [only later when he sees the TB nurse does he mention it again]. The doctor asks him about his history: date of birth, residence, employment, illness [came to clinic after coughing and loosing weight]. He complains that his work is very tiring and that he works with dust. She refers him to the TB nurse.

With the next patient there is no friendly chatting as with the previous two. The patient's body language is distant – she is turned away, with her legs and arms crossed, looking away from doctor. She has previously been treated for TB in 1999 (her second time already). The doctor asks her how she is feeling. She complains that she is tired and coughing. She is not smoking and has not experienced any weight loss. The doctor says that there is no TB in her sputum. Her symptoms could be the signs of the old TB. Before starting with the TB treatment, she will need proof. The doctor gives her some antibiotics for bronchitis. The doctor looks at the x-rays and explains and compares the two x-rays. She sends the patient for a second sputum test. The doctor asks the patient about employment, family and children. The patient remains distant and gives short answers.

The next patient is a child of about 3 or 4 years. He is in the second month of the TB treatment. The doctor notices the child's improvement in health. She changes the medication and sets up the next appointment for the child to go to the doctor and for x-rays at the False Bay hospital. Each consultation takes between 5- 15 minutes.

Observations: Community-based treatment within treatment supporters' homes

Treatment supporter home, Retreat

9 am in the morning, the patients knocks and comes into the treatment supporters home. They greet each other: how are you today. The patient sits down in the comfortable sun lit couch. The treatment supporter takes the tablets and the patient's white plastic envelope out of her treatment box. She offers the patient (and me) a cup of tea, which the patient gladly accepts. She returns from her kitchen with the cups of tea and sits down. They chat about whether there is any improvement in the patient's health and about her nausea. The treatment supporter gives her advice on what to eat. The patient does not have as much time as she usually does and drinks her pills and signs the white plastic envelope. Good wishes for the day are exchanged and the patient leaves.

Treatment supporter's home, Ocean View

It's 14:00 and the treatment supporter is expecting one patient to come for her medication. She lives in a small flat, which is richly decorated and full of photographs of her family, medals of her children's races, and of her certificates. The patient arrives with her two children – they greet and sit down. The treatment supporter offers us something to drink and disappears into the small kitchen. She returns with some fruit for the children and the cups of tea. She sits down. There is little room for everyone. The patient chats about her day and asks after the treatment supporter's family. They have known eachother for many years and attend the same church. Once the patient has taken her medication and signed to card, they leave. My presence has an effect on patient's, who may feel less free to discuss their concerns.

APPENDIX B
Monitoring System

Records should be developed for the community-based supervision to allow the measurement of their performance. Such a possible system was recently piloted in Khayelitsha and Nyanga by Chantelle Allen. She works for three NGOs – the Health Care Trust, SACLA, and Zibonele, which make up the Unit Primary Health Care Programme.

"There was chaos at the clinics - the sisters don't know how many and which patients are out in the community. They have a huge case load - 300 clients and 30 treatment supporters. There was also a problem with tracing defaulters." – Chantelle Allen

Through participatory research she has identified four main issues that have been problematic at clinics (Allen, 2001):

1. Keeping track of which patients have been placed within the community
2. Keeping track of which treatment supporter was supervising which patients
3. Ensuring quality

Through participatory research and workshops with clinic staff and NGOS, she developed several colour-coded forms that would help address these concerns in a standardised and user-friendly manner. The forms include referral, registration, defaulter tracing, supporter's caseload register, coordinators monthly quality check and DOTS reporting forms.

The system has been well received in the pilot areas, with clinic staff feeling more in control of the community-based treatment and more motivated. The system has given the treatment supporters and the TB nurse a sense of ownership and joint responsibility of their patients. The quality control form used by the supporters helped address the concerns of the clinic staff about the kind of service the supporters were offering. The community health worker coordinator checks the drug box, record keeping, and client follow up of the supporters. The scores, as well as the actions taken to address problems are reported back at district level.

Chantelle Allen was unsure, however, of how sustainable this system of formalising community DOTS would be.

"How will they continue and how much support will they need? Another question is when this process is taken to another clinic, how will it work? Will they have to go through the whole process of developing the records?" – Chantelle Allen

APPENDIX C

1. TB patient questionnaire
2. Interview schedule for TB nurse
3. Interview schedule for other clinic nurses
4. Interview schedule for treatment supporters
5. Interview schedule for Retreat Health Committee
6. Interview schedule for Community Health manager
7. Interview schedule for TB Care coordinator
8. Interview schedule for Healthy Cities coordinator

VRAELYS: TB KLIENTE

A. Vertel my meer oor u self:

Demographics, living conditions, socio-economic conditions

1. Naam
2. Ouderdom
3. Watter school opleiding het u? En die vrou/moeder van die huis houding?
4. Waar woon u? Adres & telefoon nommer .
5. Beskry u tuiste.
   a. Hoeveel mense woon saam met u?
   b. Wie is hulle?
   c. Wie verdien die inkomste? Hoe? Is dit maandeliks?
   d. Wie help u nou dat u siek is met u verantwoordlikheide?
   e. Ontvang u 'n disability (of ander) grant?
   f. Wat dink u van die grant sisteem?
   g. Is u huis/woonstel/kamer in 'n goeie kondisie? (Lek u huis, het elke kamer 'n venster wat oop & toe kan gemaak word?)
   h. Hoe veel mense deel een kamer/bed?
   i. Het u drink water in u huis en geen probleme met die riool sisteem nie?
   j. Hoe dikwels word die vullis deur die munisipaliteit weggevat?
6. Het u TB al redes een/meer keer gehad? Wanneer? Wat het gebeur?
7. Het enige van u familie of friende tans TB?
8. Is u met BCG teen TB geimmuniseer?
9. Beskry vir my wat/ hoe veel u gewoonlik eet vir:

- Breakfast
- Middag ete
- Aand ete

B.Die volgende vrae gaan oor u deelname aan gemeenskaps probleme:

Community Participation, knowledge of services: NGOs & Healthy Cities

1. Wat dink u is duie grootste probleme hier in Ocean View/Retreat?
2. Is u deel van enige komitee?
3. Neem u deel aan die TB Care/ kliniek se tuin projek of 'n ontwikklings projek?
4. Is daar "street committees" in u gebied?
5. Hoe word u oor probleme, vergaderinge, geleentheide, of "occasions" ingelig?
6. Neem u somtyds aan gemeenskaps vergaderinge deel? Hoekom/nie
7. Ken u u gemeenskaps leiers en raadgewers?
8. Watter organisasies bied hulle dienste aan vir die gemeenskap in Ocean View/Retreat?
    a. Het u al van die "Healthy Cities" projek gehoor?
    b. Het u al van TB Care gehoor?
    c. Ken u vir TB 'treatment supporters'?

C. Nou gaan ek u oor die kliniek vra:

Accessibility

1. Hoe ver woon u van die kliniek af?
2. Hoe het u kliniek toe gekom?
3. Watter reelings moes u tref om hier te kom?
4. Hoeveel het dit u gekos?
5. Hoe lank vat dit om u behandleing te kry?
6. Vir watter ander redes besoek u die kliniek?
7. Is daar 'n ander kliniek wat u eerder sou wou besoek?
8. Assosiasies met die kliniek (*vriendelik, siektes, in & uit, ongereeld,...*)
9. Wat is u verhouding met

- die TB suster?

- die ander susters?
- die doktor?
- die maatskaplike werker?

10. Hoe hinder/help elke een van die persone u met u behandeling?
11. Wat is u verhouding met die maatskaplike werker?
12. Is daar 'n onderskyd tussen die dag hospital en die kliniek? Wat is dit?

D. Ek wil u nou graag oor die dienslewering van die kliniek en die 'treatment supporters' vra:

Client satisfaction – clinic & treatment supporters

1. Wat dink u oor die TB behandeling: dat iemand toesig moet hou wanneer u u pille drink?
2. Het u al by die kliniek se "breakfast club" geeet?
3. Watter informasie het die suster/treatment supporter u gegee:
   - Oor u siekte (oorsake, gosonde kos, side effects)
   - Oor verskillende organisasies waar u vir hulp kan vra
   - Oor ander gesondheids "issues" b.v. family planning, immunisasie, ens.
   - Oor u behandelings keuses

4. Hou veel tyd spandeer u met die:
   - Doktor?
   - TB suster?
   - Treatment supporter?
   - Maatskalike werker?
5. Watter ondersteuning kry u van die
   - TB suster?
   - Treatment supporter?
6. Het die persoon tyd om na u te luister, te gesels, ...

7. Word u gespreke en gesondheids toestand konfidentieel behandel?
8. Is daar genoug privaatheid in die behandelingskamer?
9. Het u al 'n huis besoek van 'n suster of 'n treatment supporter ontvang?
10. Het die kliniek al vir u vriende en familie vir 'n sputum toets gevra?
11. Hoe sou u die TB behandeling beter?

E. Ons is amper klaar. Ek wil u net graag nog meer oor u behandeling en siekte vra:

Barriers to compliance

Ek het 'n lys van allerande redes houkom somige mense somtyds nie wil pille drink nie of vir behandeling wil kom nie. Kan u vir my se watter van hierdie redes somtyds ook vir u toepas?

- ☐ Werk
- ☐ Verhouding met die suster
- ☐ Verhouding met die treatment supporter
- ☐ U sien geen verbetering nie
- ☐ U voel baie beter/ gesond
- ☐ Die pille maak u naar of siek
- ☐ Weer
- ☐ U woom te ver
- ☐ U weet nie waar u vir behandeling moet gaan nie
- ☐ U is te besig met ander dinge (huis, kinders)
- ☐ Niemand moet weet dat u TB het nie
- ☐ U sal nooit weer gesond word nie
- ☐ TB is 'n straf van God en net Hy kan u weer gesond maak
- ☐ Other hindrances:

Baie dankie vir u tyd en vir u deelname.

QUESTIONS FOR TB NURSE

1. How do you feel about being the TB sister?
2. What do you like about your job?
3. What don't you like?
4. Describe a 'good' TB client.
5. Describe a 'bad' TB client.
6. Describe a doctor.
7. Describe the typical treatment supporter: associations
8. What relationship do you have with you clients?
9. What do you think are the reasons for TB clients stopping their treatment?
10. What do you do when a client does not adhere to the treatment?
11. What is your relationship with the treatment supporters, with the Coordinator?
12. Were you and the other sisters consulted when TB Care started working in this area?
13. What do you think about DOTS?
14. What are your views on the disability grant? Do you think it hampers or helps the situation?
15. Enabling environment...
16. From your experience, who is more likely to comply?
17. How you do deal with your daily stress? Do you have support?
18. What do you do for your own health?
19. What other organization do you work with? E.g. SANTA, TB Care, KAFDA, ...

QUESTIONS for Clinic Nurses

1. What services does this clinic offer?
2. Are the goals of the service stated? What are they?
3. What are the clinic's performance indicators? How is the service's efficiency tested?
4. Do other clinics run things differently? How? More or less effective?
5. What are the health targets of this clinic?
6. Are curative or preventative services funded more?
7. How does the clinic recover costs? Do client pay any fee?

8. What roles do you play: at the clinic and at home, community?
9. What - in your opinion - are the main health problems in this area?
10. What are the main social problems here?
11. What are other problems this community faces?
12. Rank the occurrence of health problems in this community.

13. Describe the community you serve (size, age structure, geographic disposition).
14. What do you know about the morbidity and mortality rates?
15. What is the average number of clients you serve? TB & other
16. What problems in service delivery do you see? How would you like to change it?
17. Have there ever been any drug shortages: BCG, others? How readily are they available, accessible? Is the regular supply sufficient? What problems have you experienced?
18. How you do deal with your daily stress? Do you have support?
19. What do you do for your own health?
20. What other organization do you work with? E.g. SANTA, TB Care, KAFDA, ...

21. Do you/does the clinic have contact with community leaders? Who are they?
22. Do you have any working contact with other local government branches?
23. What role do you think local and national government should play?

24. How would you describe staff morale?
25. Do you think that you are being paid fairly for what you do?
26. Your authority in decision-making?
27. Are the managerial procedures clear, do you have a specific job description, performance guidelines, and supervisory guidelines? Does the clinic have and operate according to a shared vision?
28. Do you receive sufficient support and training? What recent training did you attend?
29. How is your performance evaluated?

QUESTIONS: TREATMENT SUPPORTERS

1. Who is TB CARE?
2. What does DOTS offer?
3. What is the role of a treatment supporter?
4. How much time do you spend with each client?
5. What do you have to do?

6. What are the main health problems in your area?
7. What are the main social problems in your area?
8. What are other big problems in your community?
9. Are you part of any other committee?
10. Do you have contact with other organizations/ community leaders/ councilors?
11. What other organization do you work with? E.g. SANTA, TB Care, KAFDA, ...
12. What local development is happening in your area? Housing, Economic development, ...?
13. What do you think the role of local/national government should be?

14. Describe the community you serve.
15. What is the average number of clients you serve? TB & other
16. What is your relationship with
    - the nurses,
    - the client,
    - the coordinator,
    - other treatment supporters?
17. What qualities should a treatment supporter have, to be good?
18. What do you like/dislike about this work?
19. What other roles do you play?
20. How has being a treatment supporter affected your other roles?

21. How does the community perceive you?
22. How do the nurses perceive you?
23. Describe the TB sister, other sisters. Associations
24. How would you describe their staff morale?
25. Describe a typical 'bad' client.
26. Describe a typical 'good' client.
27. What do you think are the reasons for TB clients stopping their treatment?
28. From your experience, who is more likely to comply?
29. What problems in service delivery do you see? How would you like to change it?
30. Have there ever been any drug shortages?
31. What do you do when a client does not adhere to the treatment?
32. How do you deal with a 'difficult' client?
33. How do you deal with a "scollie", child, HIV client?

34. Are the managerial procedures clear, do you have a specific job description, performance guidelines, and supervisory guidelines? Do the treatment supporters have and operate according to a shared vision?
35. Do you receive sufficient support and training? What recent training did you attend?
36. How is your performance evaluated?

37. How you do deal with your daily stress? Do you have support?
38. What do you do for your own health?
39. What are your three biggest problems in your life?

40. If you could do anything to help in the fight of TB, what would you do?

QUESTIONS for the Retreat Health Committee

1. What is your role?
2. Who are your members?
3. How are decisions made?
4. What issues have you dealt with this year?
5. What roleplayers do you work with?
6. What role do you think local govt should play in health?
7. Do you have contact with other sectors?
8. What role have you played in dealing with TB?

Questionnaire: Community Health manager

GENERAL

1. What is your role as TB Coordinator?
2. What are your objectives?
3. What strategy do you use to achieve these objectives?
4. What challenges are you facing? What have been your successes?

MANAGEMENT

5. How are records used?
    - What performance indicators do the clinics use?
    - How do you monitor these?
    - How do you manage those clinics who do/not meet the requirements?
6. Is the clinic in Retreat run differently than the one in Ocean View? More or less effective?
7. How are you addressing staff morale and other management concerns? What is the situation in Retreat and in Ocean View?

PERCEPTION OF COMMUNITIES

8. What - in your opinion - are the main health problems in both areas?
9. Rank the occurrence of health problems in both community.

What are the main social problems?

STATS

10. Please explain the statistics received from the Health Officer:
    - number of children & occurance of primary TB
    - definition of "other" on supervision
    - numbers do not add up: total no. of patients & no. of male & female
11. What are the stats for the number of MDR-TB, HIV co-infection in Retreat and Ocean View, population, infant mortality in both areas?

COMMUNITY-BASED TREATMENT

12. According to the stats the clinic staff carry the most of the TB treatment burden.
    - Are they/you receiving the support you need from the NGO's and the community treatment supporters?
    - What are the challenges/advantages?
    - How would you like to see this relationship and support develop?
    - What role should they play?

TREATMENT APPROACH

13. What are your thoughts on DOTS and TB control?
14. Is the emphasis more on prevention or on curative services? Give examples.
15. How would you describe a holistic approach to TB? To what extent can treatments be integrated?

HEALTHY CITIES

16. What role has/will/could Healthy Cities play in the control of TB?
17. How is the pilot project doing?
    - Successes and challenges?
    - What is necessary for it to succeed?
    - What is the level of community participation?
18. How would you describe the political commitment to
    - Health,
    - TB, and
    - Healthy Cities?
19. What percentage of the budget is allocated to
    - Health and
    - TB?

Questions: TB CARE Coordinator

Brief history of project:

1. What are the aims & objectives of TB Care?
2. What are your working principles?
3. **Is the project financially stable?**
4. **Do you have sufficient resources: staff, equipment, materials**
5. Describe the staff compliment: number of staff and their titles.
6. What services do you offer? (home care, follow up, health education,...)
7. Describe your target population: geographic area, organizations vs. individuals
8. How are your boundaries defined?
9. Has TB Care undertaken a community-based research to determine the socio-economic, demographic and health characteristics of the target population – to assess their needs?
10. To whom is TB Care accountable?
11. How do you ensure feedback?

Decision-making & community participation:

12. How did you start the project in Retreat & in Ocean View?
13. How did/do you consult with the community, health authorities, health committee?
14. Where does TB Care make contact with those in need of your services – besides clinic?
15. How do you select treatment supporters?
16. How are decisions made at TB Care – i.e. decision-making body?

17. Who sits on this body? Number of project staff, community representatives: how selected?
18. How are decisions made?
19. How does staff participate in making decisions?
20. Do you receive/offer in-house training?
21. What problems & successes have you had around participation?
22. Has your community participation ever been evaluated?
23. How do you keep the community informed and involved?

Access to services:

24. Do you offer outreach services? E.g.?
25. Do you offer after-hours services?
26. How do you ensure that your service reaches those most in need?
27. When do does TB Care turn away a person?
28. How does TB Care provide equitable service in a community that is divided?

Specific involvement in Retreat & Ocean View:

29. What is your role?
30. Describe each area – their socio-economic, political and health characteristics
31. How do these areas differ?

32. What relationship do you have with the clinic staff?
33. What relationship do you have with the treatment supporters?
34. What problems are you experiencing in your work with these volunteers? (incentives, abuse of power, participation)
35. What other benefits does TB Care offer for its 'volunteers'?
36. What relationship do you have with the health committee (Retreat)?

37. How does TB Care ensure good service delivery? How are your services monitored?
38. What do you see as TB Care's shortcomings?
39. How do you balance curative and preventative needs of the community?
40. Do treatment supporters offer preventative services?
41. Do you feel that the treatment supporters have been utilized optimally in Retreat and in Ocean View?
42. Describe how the successes & challenges have been different in both areas and why.

Intersectoral activities:

43. Does TB Care collaborate/partner with other NGO's or organizations to address the basic health needs of the community?
44. Are you aware of any other socio-economic/LED projects being run?
45. What is your relationship with the coordinators of the Healthy Cities project in Ocean View?
46. What is your opinion on the Healthy Cities concept and its implementation in Ocean View?
47. Do you have any contact with other municipal sectors besides health? Describe your contact/relationship.

Training of treatment supporters:

48. What training does TB Care offer? (nutrition, housing, drug & other abuse, employment, HIV/AIDS, health promotion, ...)
49. How do you test for the manuals' accessibility and relevance?
50. How does TB Care help a treatment supporter group to become sustainable and autonomous? (Training e.g.: how to run meetings, organize services, evaluate interventions, manage funds, teach community members health skills, fundraising)

INTERVIEW: Healthy Cities project coordinator, Ocean View

1. What is your position and role in this project?
2. What are the aims and objectives of this project?
3. What is your strategy to achieve these?
4. What indicators are you using to measure your success?
5. What is your definition of a supportive environment?
6. Your experiences in consulting the community, agencies, groups?
7. Does Ocean View have a vision?
8. How have you addressed TB?
9. What role does this project play in building :
    - Community action
    - Supportive environments
    - Partnerships between the health sector and local government organizations
    - Strengthening institutions

10. Comment on (challenges & successes):
    - political commitment to the Healthy Cities project (budget allocations; authority)
    - intersectoral action
    - sustainability & equity

11. Other issues & concerns

APPENDIX D: QUOTES

Main Findings

A. Environment

B. Perceptions of TB

C. Community Participation

D. Equity

E. Comprehensive Approach

F. Health Care Management

A. ENVIRONMENT

Living Conditions

"I'm supported by my brother and sister – they occasionally give me food." – Patient, Ocean View

"I'm unemployed and I have a wife and daughter in Std. 6, who I have to provide for. They live elsewhere. I'm feeling very helpless. It is difficult from a man's point of view because I'm unemployed and I have no support or help." – Patient, Ocean View

Nutrition

"We have one loaf of bread and one liter of milk for the whole family per day [two children and two adults]. Sometimes we have to go hungry. Last week we bought a tray of eggs – so we had eggs the whole week. Sometimes I go to the loan sharks to borrow R 20 on a Monday for food. Then we have to pay back R 26 on Friday. There isn't always enough money for fruit and vegetables." – Patient, Retreat

"I eat anything that is available. Last week it was oats and milk. I get some soup from the caretaker's sister and then I eat at the breakfast club: Milo, milk, chicken." – Patient, Ocean View

"Food is scarce. I usually just have a slice of bread and coffee." – Patient, Ocean View

"My mother really looks after me now that I am sick. She also read the booklet and now we eat healthy food." – Patient, Retreat

Housing

"The biggest need is housing and employment." – Nurse, Retreat

"I live with my mother, 2 brothers, one child and myself and my child in our [one bedroom] flat." – Patient, Retreat

"I stay in a shack on someone else's property. I no longer get along with them, so there's uncertainty about where I'll be staying. The "hokkie" is very small and I can barely move around. I'm going to ask the man if I cannot make it a bit bigger. I get water from the neighbours."- Patient, Ocean View

"Many people living in shacks and in the hostels at Mountain View do not have any water in their houses or floors or ceilings."- Treatment supporter, Ocean View

Social and Developmental Concerns

"I would also like to see them stop using kids to sell drugs. Drugs and alcohol abuse is very high here. They need to focus on the youth, especially about AIDS and teenage pregnancies. For example, a 7 year-old child was found drunk and smoking with his parents. That's child abuse." - Treatment supporter, Ocean View

"I feel safe – but it can get very dangerous with assaults and stabbings – especially on Fridays and Saturdays. During the day it is safe but it is best to stay in during the evenings." – Patient, Ocean View

"These socio-economic problems [in Ocean View] lead to patients defaulting from their treatment." – Doctor.

"There is a greater problem with overcrowding in Ocean View than in Retreat." - Doctor

Development

"The [Ocean View] community seems to have lost hope and initiative." – TB Care Coordinator.

Education

"One girl is 16 and she already has her second child." - Treatment supporter, Ocean View

Retreat and Ocean View clinics

"Another great concern is that we are treating more children than adults for TB in Ocean View." – Nurse, Ocean View.

"My mother, brother and my child have TB as well." – Patient, Ocean View

"My mother is a suspect and my brother is on treatment. My child had it before and now again [she lives with mother, 2 brothers and 2 children – first time TB case]." – Patient, Ocean View

B. PERCEPTIONS OF TB

Cause of infection

"I've had TB four times already. I think I got sick again because of the loss of my parents – I lost a place to stay and had to sleep wherever [outside] and often it was cold. I also smoke a lot." – Patient, Ocean View

"I think that I'm sick because of where I stay. It's unhealthy. I live very close to the outhouse and I have no water or toilet. It is also very cold. " – Patient, Ocean View

"I got TB in prison – but I only discovered it once I returned to Ocean View." – Patient, Ocean View

"I think I got TB again because of all of my worries and the fighting with my boyfriend." – Patient, Retreat

Compliance

"I have no problem coming. The nurse stands by me and I'm forced to drink my pills. Others hide them – druggies will take anything for a high." – Patient, Retreat

"They should give patients like me the pills because I am doing it for myself. I'd take them – I don't like this up and down to the clinic everyday." – Patient, Ocean View

"I just have to do it. There is no other way" – Patient, Retreat
"Its healthy. If I can't come it's my own fault. You have to do it for your own health. I have walked to the clinic for my son too." – Patient, Retreat

"I prefer to come and take my pills here. I know I have to come and everyone sees that I have taken them. If I take the pills at home no one sees it and they think that I throw them away." – Patient, Retreat

Enhancers to compliance

"There are no problems with the treatment. Even when the weather is bad, I'll come because I don't want to infect my child and my friend."- Patient, Retreat

"When I feel depressed, then I force myself to come. I stayed away for 1 month [after 3 months of treatment] but then started to feel really sick again – close to death. This is what motivates me to come now." – Patient, Retreat

"I chase after them, that's why we have such a high compliance rate." - TB nurse, Retreat

"It is difficult to say who is more likely to comply. It depends on their motivation and that's personal. What's important is continuity. The patient builds a relationship with the nurse and patients don't like it when there is a change in nurse." – TB nurse

"In the end the patient who is open minded and is able to face reality and take responsibility will finish their treatment."- Treatment supporter, Retreat

Barriers to compliance

"There is no organisation to help with substance abuse. It's very necessary." - Treatment supporter, Ocean View

"The pills make me hungry and you need food and drink. If I drink them [pills] on an empty stomach, they make me dizzy."- Patient, Retreat

"What would make things easier is if someone could supervise me at home – or if I find work they can supervise me there." – Patient, Ocean View

"Perhaps they could offer some food more regularly."- Patient, Retreat

C. COMMUNITY PARTICIPATION

Perceptions of community participation

"While in other areas home remedies, for example, are more common, people here have been coming to the clinics for everything and have become dependent on us even for the smallest thing."- Nurse, Retreat.

"It can be overwhelming - people are so used to having things done for them. They always ask for a referral letter, even if it is just to apply for a new ID. They assume that if they don't have a letter, they will not be attended to."

"Most people want jobs first, instead of skills and they don't want to work for too little money." – TB Care Coordinator.

Community participation within clinics

"The Health Committee is a powerful structure. It can decide whether or not a nurse can work at the clinic. The community is not aware of this. The clinic does not promote the idea of the Health Committee enough."- TB Care Coordinator.

"They no longer wanted to volunteer their time. Those who volunteered to be part of the Health Committee were also part of other committees and the committee was not considered truly representative of the community. - Nurse, Ocean View.

"Last year I helped out every second day at the clinic – rotating with the other treatment supporters." - Treatment supporter, Ocean View

Community participation and treatment supporters

"While they may not be dealing with that problem [difficult TB patients are referred back to the clinic], they are actually removing a certain load from the clinic, and let the clinic focus on those problem cases." – SPM Manager of Community Health

"I like the idea of community participation because while you are training people – it's in a way of developing awareness in the community and I think we need this awareness. I am keen in getting the community involved. There is a world of untapped resources." – SPM Manager of Community Health

TB Care's role in community participation

"It is very difficult to find the right people. For me it is important that they are willing to accept the creepy crawlies into their homes and that they are willing to work for free. And even on holidays." - TB Care Coordinator

"The only problem is that treatment supporters have dropped out. They are no longer interested and are full of excuses." – Treatment supporter, Ocean View

Community participation and the Healthy Cities Project

"We have big plans for the future. We chatted with the new councilor and we plan to continue with the cleaning campaign - in Lapland, all schools, churches, etc. to be involved."- Treatment Supporter, Ocean View

"Besides communities being mobile, which create difficulties for community participation, people want to see change or else lose interest." - SPM Manager of Community Health

D. EQUITY

Equity and clinic-based treatments

"The container is always ready when I come and I just walk in, drink my pills, and sign the card." - Patient, Retreat

"The clinic hasn't brought the folders or the tablets for the patients. I depend on the patients to tell me what pills they need to take and how many. I used to get white plastic folders (medication compliance records), which the patients should sign. But it's not happening. You can talk yourself blue in the face – I don't feel like talking anymore. I work out my own system." – Treatment supporter, Retreat.

"If I had known that she was going on holiday, I would have given her a present." – Patient, Ocean View

"She is a very good nurse and person. She knows how to handle anyone – from babies to grown ups. I trust her." – Patient, Ocean View

"She is good for us. She encourages me and she is the one who organised the garden project."- Patient, Ocean View

"I can always come to her and ask questions about my disease and she always makes the time to listen." – Patient, Retreat

"She is busy, but I believe that she will make time to listen." – Patient, Retreat

"She always has a few kind words."- Patient, Retreat

"We understand each other. It's business." – Patient, Retreat

"We have a good understanding. She is very nice. I have no complaints. She laughs and asks how it's going." – Patient, Ocean View

"I had to wait for her for too long. I wanted to see her about the disability grant but then left for home." – Patient, Retreat

"She is a kind woman. The voucher once a month is little but I can get by on it."- Patient, Retreat

"She is good. She helped me with problems and you don't have to wait too long."- Patient, Ocean View

Equity and community-based treatment

"She [TB nurse] encourages me and talks to me almost like a mother and she always makes me a cup of tea." – Patient, Retreat

"When I'm finished with my treatment I'll buy her [TB nurse] a big bunch of flowers. I love her. I grew up with her. She's here for me and I can come to her anytime and ask her for advice and help." – Patient, Ocean View

"She [TB nurse] makes my treatment easier. She has helped me accept the fact that I have TB." – Patient, Retreat

"She {TB nurse] often gives me hugs." – Patient, Retreat

"She's just as good as the sister. If I forget to come for my pills, she brings them to my home. She's lovely and easygoing. We chat a lot and I trust her." – Patient, Ocean View

"She [treatment supporter] is just as nice as the sister at the clinic. We talk and I look forward to coming in the morning." – Patient, Retreat

"Some bring me something small as a thank you: chocolate, yoghurt, dried fruit, fish. It doesn't happen often though." - Treatment supporter, Ocean View

"It costs me R25 per week to get to the clinic. I've been praying for [treatment supporter] because it is much closer here." – Patient, Retreat

"It's very far, especially when it rains. I get very wet and tired. I live just down the road from [the treatment supporter]." – Patient, Ocean View

"I have to go and take my son to school and if I'd have to go to the clinic, he would always to be late. Coming to [treatment supporter] I can come in the afternoon after I have fetched him from school." – Patient, Retreat

"I know them and like all of them. They are friendly and chatty." – Treatment supporter, Ocean View

"I have learnt to be patient and listen to their burdens." – Treatment supporter, Ocean View

E. COMPREHENSIVE APPROACH

TB treatment services

"We realise that you have to speak to the whole person, instead of focusing on one disease. But we don't have the time to do that. If you spend too much time with one client, others in the waiting room get upset. We've also been told by the chiefs that we should spend less time counseling, even though it's important so that you don't treat a person for something completely different." – Nurse, Retreat.

"We do more curative work and administration – they [management] are not interested in preventative services or in empowerment." – Nurse, Retreat

"We channel social cases to the social worker. We know about what's available in the community – but now even the churches are charging R 2 for a meal- there's a lack of everything." – Nurse, Retreat

"I find it hard to differentiate between TB, HIV, STD because a lot of TB patients are also HIV infected and that is going to be more and more of the case. And so I think if you have a TB supervisor who knows nothing about HIV, that hasn't had an insight and isn't prepared to deal with HIV positive patients – then that isn't good enough. I don't want that we have to send someone to treat that patient for TB and then somebody else for HIV. It makes no sense." – SPM Manager of Community Health

Comprehensive approach: nutrition

"We receive donations from the butcher – some bread and bones - and from the vegetable shop. When we need extra money, we collect some money from the nurses." – TB nurse, Retreat

"I cook soup and other meals for TB patients at the clinic – I've been doing it for the last 4 years. I also cook for the people living in the squatter camp nearby – they will also end up with TB. I receive donations from our butcher."- Treatment supporter, Retreat

"At the moment I'm feeding two children even though their treatment has finished. [The TB Care Coordinator] thinks that I'm spoiling them people - especially the parents. But their mother is working and the father is a runner for drugs." – Treatment supporter, Retreat

"I give clients something to eat – an apple, orange, or a plate of food on Thursdays. I'm not spoiling them - I've got leftovers. I feel more like a social worker here - I even take kids to school." – Treatment supporter, Retreat

Comprehensive approach: Health Education

"One of my sons is a fisherman and he is smoking and drinking. I spoke to him and asked for his cooperation. I use pictures and the book from the training to explain to him how he is infecting others and about drug resistance and he was very worried and has now stopped smoking." – Treatment supporter, Ocean View.

"We have been given telephone numbers [of organisations] to hand out to alcohol and drug abusers. Otherwise the only other help is the clinic or CAFDA." – Treatment supporter, Retreat.

"Agencies should share their roles and become one united 'force'. TATSA could be responsible for training, SANTA for community-based DOTS, and TB Care could be responsible for social services. But this is still not happening because of funding and personality issues. I imagine this one agency to have different departments: monitoring and managing treatment supporters, training, social work, food (vouchers, etc.), HIV, and substance abuse. But years of working separately is deeply entrenched and hard to let go." – TB Care Coordinator

F. HEALTH CARE MANAGEMENT

Clinic management

"All you have to do is to focus and if it works for that and if you have the finger on the pulse then everything else will come right because you are working on what makes a difference. And it rubs off. I found that it is extremely rewarding realising that you don't need to focus on everything." – SPM Manager Community Health

"People felt overwhelmed because there are so many reasons why the people interrupt their treatment. There have been so many studies and nothing is really helpful because there are a million of reasons and it doesn't help them at the clinics." – SPM Manager Community Health

"We are given targets to cure 85% of TB patients - but what can you do if a patient doesn't want to be cured? There is nothing a nurse can do to achieve it. The managers are only interested in achieving stats – they don't realise what one has to." – Nurse, Retreat

"The funny thing is that by focusing on the new cases, which are supposed to be the ones that are easy to treat, we actually realised that there was a major impact made on the re-treatment cases." – SPM Manager Community Health

"They felt that they could tackle that and the funniest thing again is that by closing the gap they generated a lot of activity around the patients and that had another spin off: treatment interruptions started to go down – because they were doing all the right things to get those patients to give the sputum." – SPM Manager Community Health

"Recently SPM also appointed a TB Coordinator, who makes times for things that have to be done and does them with the clinic staff – enforcing a routine and supports them instead of doing it for them." – SPM Manager Community Health

"Each area has different needs. It's important to train the right person who is interested in TB to take responsibility for DOTS. Having only one person to do TB will free up that person's time to do follow-ups for recall. I would be able to do this if I

were only solely responsible for TB [also the clinic manager]." – TB nurse, Ocean View

"A successful cure rate depends on a reduced workload and an increase in manpower." – TB nurse, Retreat

"They only concentrate on 001 category: new sputum positive, pulmonary TB – but there are also other categories that are not sputum positive. We still have to deal with the other categories." – Nurse, Retreat

"As soon as the cure rate dropped again to 60%, the managers first complain. They don't really recognise the hard work that goes into high compliance rates. We try our best and sometimes the rate drops. They should look at the percentage from a broader perspective." – TB nurse, Ocean View.

"There is also no time to build relationships amongst ourselves." – Nurse, Retreat

"We are very busy. There is no time for follow-ups – for example for immunisations, defaulters, or home visits." – Nurse, Retreat

Treatment supporters

"At the moment we're too paternalistic and we haven't set any clear goals." – TB Care Coordinator

"It is very easy to say let's train community supporters – especially in the areas where they have low cure rates. But if the programme is not well organised, getting community supporters isn't going to make any difference – it's only going to make it worse. So you've got to improve the programme – the community supporters cannot work in isolation – they've got to be linked to a working programme." – SPM Manager Community Health

"They need to respect clients and continue to build the relationship we started at the clinic through support and motivation." – TB nurse, Ocean View

"I think that the treatment supporters in Retreat are not used optimally. They only follow orders and do not take the initiative. If I don't follow up things break down. They need more training – training to empower them." – TB Care Coordinator

"They make my job easier." – TB Nurse, Retreat

Communication

"We need to communicate - nurses and treatment supporters. We are fundraising or same events and approaching same groups for funds." – Treatment supporter, Ocean View.

"She [TB nurse] is dedicated and makes you feel good about yourself. She listens and supports you." – Treatment supporter, Retreat

"Some nurses think that the TB nurse just sits all day. Management finds fault easily and there is too little praise." – TB nurse, Retreat

"I think that the clients may have been getting too much attention. When a client comes to complain about a treatment supporter, she [TB Nurse] feels she cannot approach the person directly in fear of retaliation from the supporter." – TB Care Coordinator.

"I have a very good relationship – we know each other – they like me and I also them. We chat and laugh together. The one is also from Simon's Town like me."- Treatment supporter, Ocean View

"[TB nurse] is very busy and I have real respect for her. She is supportive if I ever have any questions."- Treatment supporter, Ocean View

"I have the feeling that [the TB nurse] sees the TB patients as HER patients and she wanted us to do the work at the clinic and not at our homes." – Treatment supporter, Ocean View.

"So you see that if you don't have trust – then you need to work on that trust relationship, which means time from the clinic staff. There are no short cuts. You can't just say that these people are really great and send your patients there." – SPM Manager Community Health

"She doesn't trust the treatment supporters' ability to treat the clients and is afraid that the trust and relationship the clinic has built up will be lost. This is why she does not want to send the supporters out into the community." - Coordinator

"She's a good person. She supervises us and I have a good relationship with her. She has a nice way of talking and explaining. We really depend on her and are grateful. She comes to the treatment supporter meetings – last year she didn't have any time for individual house visits."- Treatment supporter, Ocean View

"I can call her anytime if I have problems." – Treatment supporter

"The others are getting away with being disrespectful. I am always on time and don't see why the others cannot do the same. It's rude." – Treatment supporter, Retreat.

"I'll be at the clinic for a meeting and the other supporters don't show up and don't make an effort to come – BUT it's part of the job! They are always full of excuses."- Treatment supporter, Retreat.

"No real activities have been planned or done. For two years I have been doing a rummage sale by myself. If we do have fundraising activities, I will get involved – but there aren't many." – Treatment supporter, Retreat.

"Staff are encouraged to share their successes and failures and to work it out themselves. I've tried to tell them what to do and to give them advice but that didn't work. This way is better." – SPM Manager Community Health

"There were very different results across the clinics. Ocean View was very resentful and defensive about having had such low cure rates (38%). I asked those who are doing well and those who are not, to come together and encouraged them to share their experiences. Ocean View then picked up ideas and worked it into their own model instead of me telling them what to do and pushing them. Now they didn't have any excuse. It could be done by other clinics – 85% has been achieved by all of them at some stage or other." – SPM Manager Community Health

"But let me tell you. If you look at the last quarter – for the very first time, over the last four years, we can see a difference – and that is because the others are following the

same process. We've been very systematic about sharing lessons at the Metro level. And they are on to it – they have caught up." – SPM Manager Community Health

Incentives

"If the voucher will not make a difference in their lives, then they don't get it. We don't give to drug and alcohol abusers, people who receive some form of grant or a pension." – TB Care Coordinator.

"There is the problem of dependency." – TB Care Coordinator

"The nurses sacrificed their increase to pay for it [incentive for treatment supporters]." – TB Care Coordinator.

"Incentives are a very good contribution to the success of community-based treatment. It's all very well to talk about volunteerism – and volunteerism is great for people like you and I who have got the basic needs met – but it's not sustainable when your basic needs are not met. I find that having an incentive, which is not meant to pay for the work but to make it like it's a reward – a pat on the back kind of thing. I think that gets people going in the situation we have in these marginal communities living here. It's got to be. Without incentives they've got no chance to survive." – SPM Manager Community Health

"We used to get R40 – but now it's only R30. But it's not about the money but what you can do for the community" – Treatment supporter, Retreat.

"Many lie about the number of clients the have to get more money for food and electricity. Some are very poor themselves and take from the donations of food and clothing." – TB Care Coordinator

"Acknowledging the results is a way of rewarding the clinic staff for a job well done – this is something we are not very good at. We need to celebrate the good results. We present certificates for jobs well done. We also give the TB nurse a special pat on the back - a voucher of R 20 to the TB nurse and a R50 voucher for the staff. " – SPM Community Health Manager

"She is the one who makes sure that things happen - records, etc.." – SPM Manager Community Health

"You can't think back to nine months ago. It's not easy. So people lose track of the cause and effect – you think that if you make an effort you're going to see the rewards. But you lose track of that relationship between effort and reward and you give up." – SPM Manager Community Health

"Councilors, head of portfolios and the mayor have been involved in ceremonies and in the presentation of certificates etc. They get their picture in local paper and expose

those clinics that did well AND those that didn't. Councilors show concern for those who were not doing well or praise the clinic for good results. This helps to boost the morale and make staff and treatment supporter feel important. It generates a lot of energy and activities around the patients and staff. I prefer to encourage the staff and reward them instead of giving them advice." – SPM Manager Community Health

"I deliberately stay clear from their success – important that the manager is supporting instead of the hero." – SPM Manager Community Health

"But at end of day all it depends on the health worker – no one else." – SPM Manager Community Health.

Monitoring Systems

Clinic staff

"The administration is complicated because it is devised from National – and sort of 'imposed' by WHO. We collect information and pass it on instead of using it as a management tool at local level." – SPM Manager Community Health

"They are too simplistic, for example, they are only about DOTS but there is far more to a TB sister's job – such as admin, time spent counselling, probing, referring, etc.

This is lost in stats and is an unfair reflection on nurses' job and responsibility." – Clinic manager, Retreat.

"We must provide National with this information. So we give it to them quickly, pass it on and forget about it. Then we look at what we need for our own management of the process at the local level and to get our staff to understand, get interested, get their buy in, give them the ownership of this process." – SPM Manager Community Health

"Evaluation systems are not geared to getting the people excited at the local level. They are geared towards passing on information to the higher levels – so that the higher levels can satisfy the requirements of whatever. And then feedback comes so late." – SPM Manager Community Health

"There is a lot of duplication. We use what works for us and have put together a compliance file from which we generally work and then later fill in the other files, register, and the quarterly report." – TB nurse, Ocean View.

"We had to go back on the 58% and put a name and a face they can relate to before they could understand. We had to go back to the register." – SPM Manager Community Health

"7 years ago we never used to evaluate the service ourselves and we never knew the cure rate. Having to evaluate and work out the stats ourselves has been an eye

opener. As a result we looked at our own attitudes to patients. For the previous quarter we were up to 89% cure rate." – TB nurse

"We have to do the stats ourselves, even though we hand them in to the statistician. It's a duplication of work." – Nurse, Retreat.

Treatment supporters

"I find that following up and monitoring and supervising the community supervisors is very important and unfortunately not all NGOs are doing that." – SPM Manager Community Health

"I only see her [TB Care Coordinator] at the monthly meetings – only very seldom does she do home visits. Nobody has come for whole year to check the TB medicine box." – Treatment supporter, Retreat.

"Performance has always been perceived as inputs they are putting in and we don't want to be funding based on input. So an NGO will say they've done this and that – who cares what they have done if it makes no impact, if your outcomes are not good? Who cares?" – SPM Manager Community Health

DOTS

"I see problems at the clinic [DOTS]: We've been taught to watch when clients drink their pills. I've seen that some just put their pills into their pocket." – Treatment supporter, Ocean View

"I give pills to those I think are dependable. If they are not dependable – then I ask them to come later if they missed their normal time to come for their pills. Or I walk to their house and drop off the pills. Eventually it all gets sorted out." – Treatment supporter, Retreat

"One of my clients was a mother with a young sick baby. She asked me for a week's amount of pills. I gave it to her as an exception. Now my new client is the child's father and he complained to the doctor and nurses that it's not fair that he couldn't get a week's worth of pills from her. I wanted to give up supporting all together. The sisters were talking behind my back, adding to the story and making things worse." – Treatment supporter, Retreat

"There is a big difference between coming with ideas instead of imposing them. But no model is cast in cement. They are only used to anticipate what could happen but not to be followed according to every detail. You need to adapt it to your own situation." – SPM Manager Community Health

Healthy Cities project

"We are still focusing on the big picture of communication and highlighting and raising issues. I think that a measure of success is that groupings within community are taking responsibility for issues in community – for example the involvement of the crèches and primary schools in the clean up - taking ownership."- Healthy Cities Coordinator

"The Healthy Cities Project is not at a high point at the moment – but it has a lot of potential." – SPM Manager of Community Health

"How much you can deliver depends on your budget and on the cooperation of other departments and if you don't deliver then you disappoint the community, which has an impact on participation and on your credibility." – Healthy Cities Coordinator

"People feared losing their credibility." – Healthy Cities Coordinator

"I can only raise an issue and push ideas. The rest is up to departments to become involved. For example, to address the need of a dumpsite in the Noordhoek area, I depend on waste management to act." – Healthy Cities Coordinator

"I'm concerned about duplication, confusion and coordination issues." – Healthy Cities Coordinator.

Tygerberg Agenda 21 group has a budget of 3 million for two years – our Healthy Cities is living off R 10 000." – Healthy Cities Coordinator.